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Experiences of informal care for mothers with schizophrenia and related disorders: listening to the voice of mothers and their primary supporters

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ABSTRACT

Psychiatric reforms promoted the integration of the severely mentally ill in the community and increased their possibilities to determine their own life paths, have partners and start their own families. However poor parenting outcomes have been described among some of these parents, as well as poor cognitive, developmental, health and social outcomes in some of their children.

Objectives and methodology: This research studied the experiences and needs of support in parenting of women with schizophrenia and related disorders, from the perspective of mothers and their caregivers in two contexts with different organization of mental health care. Fifty interviews were performed in the regions of Granada (Spain) and Mendoza (Argentina), and were analyzed through qualitative content analysis.

Results and discussion: Mothers and caregivers were characterized according to socio-demographic and clinical characteristics. Positive aspects and strengths in parenting were identified by almost all participants, as well as difficulties in several areas of childcare. These included having negative feelings about motherhood, having difficulties in dealing with the overload of tasks, having difficulties in maintaining discipline of children and in interacting with them, and lacking adequate material conditions for childcare. Participants talked about several aspects of illness that affected parenting, but also mentioned other personal and contextual aspects that could hinder or be supportive in this respect. Support from their close social network was considered as fundamental for parenting. Dynamic of support was described in terms of who was providing support in daily lives, which activities of support were performed, how support was requested or provided so to be acceptable, and how given and received support was being valued. Several problems were identified in this dynamic, especially in the interaction between mothers and caregivers, and in mothers feeling displaced or hindered by the support they received. As well, most caregivers talked about the burden of care they experienced. Participants also described the support they received in parenting from mental health care and other institutions. Finally, participants identified uncovered needs of support, and needs of improving aspects of the support they were receiving. Coincidences and differences in the accounts

of mothers and caregivers were highlighted, and mainly observed in the difficulties they described in parenting, the importance they gave to received care, and the unmet needs of support they expressed. Main differences among countries were related to their different organization of mental health care, accessibility of services and availability of support in parenting, support for other social needs and support for caregivers. As well, principles of community mental health care seemed to influence some experiences and understandings of illness and caring roles participants expressed.

Conclusions and recommendations: Implications for mental health care policies and programs include the need of acknowledging the role as parents of their users and adapt the organization of care to their needs, providing support in parenting and especially preparing and supporting the role of informal carers in these aspects. It seems fundamental that mothers be active participants of their care, do not result displaced in their role, and support be provided in an acceptable way so to be effective. Caregivers need more support in their role, and burden needs to be prevented. Needs of higher care during psychotic breakdowns can be anticipated and care organized in advance.

Keywords: community mental health care, mothers with schizophrenia, experiences of maternity, experiences of support in parenting, experiences of caregivers, needs of social support

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INTRODUCTION

INTRODUCTION

Severe mental illnesses (SMIs) are a group of severe mental disorders that produce deterioration in social, personal and labor life, impeding a complete and autonomous integration of the affected individuals to their contexts (Orihuela Villameriel, 2003). Among SMIs, schizophrenia is considered as one of the most disabling disorders because of the severe cognitive, affective and psychosocial impairments it can cause in young population (Sadock & Sadock, 2000; Saha, Chant, Welham, & McGrath 2005). Despite its low prevalence, it is considered by the World Health Organization as one of the ten leading global causes of disability (Florit-Robles, 2006; Vermeulen et al., 2015), and a major public health problem (Hopper, 2007).

Since psychiatric reforms were implemented and more individuals with SMI started to live in the community, having children has turned into a common event in their biographies (Barkla & McGrath, 2000). Most studies in the last two decades reported fertility rates of around 50-59% in women with SMI, including schizophrenia. According to previous researches, around 54-80% of these mothers are the main figures of care of their own children (Abel, Webb, Salmon, Wan, & Appleby, 2005; Gearing et al., 2012), spend much time involved in childcare activities, and most express concerns about raising them (Bonfils, Adams, Firmin, White, Salyers, 2014; Savvidou, Bozikas, Hatzigeleki, & Karavatos, 2003). In comparison with their male peers, women with psychotic disorders are more likely to have children and are more frequently responsible for childcare (Barkla & McGrath, 2000; Bonfils et al., 2014; Diaz-Caneja, & Johnson, 2004).

Parenting for people with mental illness can represent a challenge for several reasons. Not only they deal with the stress all parents experience regarding their role, but also need to conciliate parenting with the symptoms of mental illness and adverse effects of medication (Diaz-Caneja & Johnson, 2004; Savvidou et al., 2003). Furthermore, parenting can be affected by unfavorable contextual aspects that commonly come along with these illnesses, including economic deprivation, lack of support, and experiences of marginalization, stigmatization and abandonment. Indeed, many women with schizophrenia and other SMI are denied in their sexual, reproductive and parenting experiences in diverse social spheres (Krumm & Becker, 2006). Schizophrenia is

considered as one of the most disabling mental disorders and is associated to higher social vulnerability (Florit-Robles, 2006; Vermeulen et al., 2015). Individuals with schizophrenia tend to count with less social support, are more exposed to violence, and frequently show more problems in the interaction with children and poorer parenting outcomes than individuals with other SMIs (Abel et al., 2005; Howard, Thornicroft, Salmon, & Appleby, 2004).

When dealing with these mothers, it is common that health and social services have a limited understanding of their experiences and needs, lacking appropriate care options (Dolman, Jones, & Howard , 2013; Perera et al., 2014). As well, informal sources of care do not count with adequate orientation about their functions and activities of support, and about strategies which would make support more acceptable and effective (Power, Jackson, Weaver, & Carter, 2011). Researchers and policymakers have been increasingly aware of the need of improving the understanding of these aspects (Dolman et al., 2013; Perera et al., 2014), and have called attention to the need of exploring alternative ways of handling mental health problems that pay attention not only to the needs directly linked to traditional psychiatric care but also to the ones originated in particular family and social situations (Torres-Gonzalez, 2011).

Until now, few studies have addressed these topics, and the ones that did have mainly focused on the experiences of parenting of women with SMI. Few have deepened into the dynamics of support within families and needs of support in daily lives of mothers with SMI, and no studies have specifically addressed the experiences of caregivers when they provide support to a mentally ill individual that has children. Moreover, most studies that have addressed some of the above-mentioned topics included individuals with diverse types of mental illnesses. Research focused on certain types of illnesses might be important when difficulties tend to be distinct or more prominent in a specific illness. This is the case of schizophrenia and related psychosis, characteristically associated to poor psychosocial functioning. Social dysfunctions are more common than in other severe mental illnesses, like affective disorders, and appear not only during acute stages of illness, but also during premorbid, prodromal and residual stages (Martin, Öngür, Cohen, & Lewandowski, 2015). Typically, individuals with schizophrenia have impaired social skills in diverse social, occupational and recreational situations, are less interested in social interactions, have less social interactions and activities, and tend to obtain less pleasure from them (Kurtz & Mueser, 2008; Martin et al., 2015). Another limitation of most studies

that addressed the experiences of parenting of individuals with SMI, is their lack of consideration of contextual aspects in the shaping of these experiences. Most studies do acknowledge the influence of contextual risk and protective factors on parenting, but do not consider the influences of context in the understanding of mental illness, parenting roles and caregiving roles. Moreover, few studies have described the influence of mental health care principles and practices on informal care, and no studies have addressed these with respect to support in parenting of women with SMI.

With the aim to address some of these gaps in knowledge and focusing on one of the most vulnerable groups of individuals with severe mental illnesses, this study explored the experiences and needs of support in parenting in daily life of mothers with schizophrenia and related disorders, especially taking into account the ways in which these needs, roles and activities of supporters were defined in contexts with different organization of mental health care.

Emphasis was put on the subjective experiences of mothers with schizophrenia, their life circumstances, social interactions, and the role of family and community in care, recognizing potential needs, problems and strategies that might appear in the process of giving and receiving support. The exploration of these aspects can inform new ways of providing mental health care based on subjective, dynamic and contextual evaluations of needs and strengths, and with high value put on non-formal care in community settings. Accordingly, the proposed research had a practice- oriented purpose, meaning that the purpose is to inform practice by “providing rich, elaborated descriptions of specific processes or concerns within a specified context”, paying attention to the perspectives of the persons that have not been considered until that moment (Haverkamp & Young, 2007, p.274). A qualitative methodology seemed to be the most appropriate to address this purpose, given its strength to provide rich descriptions and explanations of processes within their contexts. Qualitative researches are used to explain ‘the ways people in particular settings come to understand, account for, take action, and otherwise manage their day-to-day situations’ (Miles & Huberman, 1994, p. 7).

The voice of the primary figures of support was included to gain insight into the complex interactions between mothers and their caregivers, as well as to enrich the understanding of the caring processes. Primary supporters are frequently involved in child care and education (Perera et al., 2014; Savvidou et al., 2003), and might be able to put light on

different aspects of the same problem, or detect areas of conflict which might not be perceived by the woman herself.

The different possibilities of understanding needs and ways of meetings those needs in different sociocultural contexts made it desirable to frame the study under a comparative design, so that cultural influences on understandings of mental illness, roles of the mentally ill and roles of caregivers and families in general could be highlighted. Two countries with similar cultural backgrounds but opposite ways of organizing mental health care were chosen, namely Spain and Argentina. While Spain, especially in the south region of Andalucía, has developed a complex system of community mental health care, Argentina counts with mental health care mainly based in hospital psychiatry with less development of community and rehabilitation services.

As well, it is important to consider that the experiences of parenthood are influenced by the prevailing narratives of parenthood. These narratives in the contemporary western world tend to expect mothers to comply with an image of natural, perfect, self-sacrificing and only care-taker of their children (Barnett, 2005; Molina, 2006; Power et al., 2011; Valladares, 1994). Nonetheless, this study did not have the objective to analyze and criticize the contemporary narratives about maternity, but took them as a background under which the problematic takes place. The concept of *parental competencies* was used to understand parenting and its dynamics in this research. This concept is extensively applied in psycho-educative interventions for families were parents show difficulties to take care and raise their children (Sallés & Ger, 2011), and was chosen because it permits a flexible and holistic approach to parenthood, that integrates social networks and community resources as fundamental for a satisfactory parenthood (Sallés & Ger, 2011).

The present study is organized in five chapters. First, a literature review was conducted to provide a theoretical framework under the public health model of social determinants of health. As well, existing evidence on the topics of parenting in individuals with SMI and social support as a resource of care were revised. The second and third chapters present the purpose and objectives of study, introduces methodological considerations and describe the methods of collection and analysis of data. In the fourth chapter results are presented in five main sub-sections, namely socio-demographic characteristics and description of contextual aspects, experiences of parenting, experiences of support from informal sources of care, experiences of support from formal sources of care, and needs of support in parenting. The fifth chapter discusses the obtained results ordered under the

same sub-sections than the results. Finally, conclusions and recommendations are presented.

CHAPTER 1:
LITERATURE REVIEW

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LITERATURE REVIEW

As was introduced in previous pages, parenting can be especially challenging for women with schizophrenia and related disorders for several reasons that include challenges brought up by childcare for any parent, difficulties caused by symptoms of illness and adverse effects of medication and adverse contextual characteristics. Both, mental illness and parenting can be strongly influenced by contextual aspects, especially by support provided by significant others.

The literature review was organized under three main sections, starting with the provision of a theoretical framework under the public health model of social determinants of health and a revision of the importance of social determinants in programs of mental health promotion. Following, a section that reviews main issues related to parenting and severe mental illness is presented. It includes a revision of the experiences and difficulties of these parents, the consequences of parental mental illness on children, and the interventions designed to improve parenting and child outcomes, as well as the perspectives that have guided these interventions. Finally, social support as a resource of care was reviewed, considering its effects on mental illness, on parenting and its consequences on caregivers.

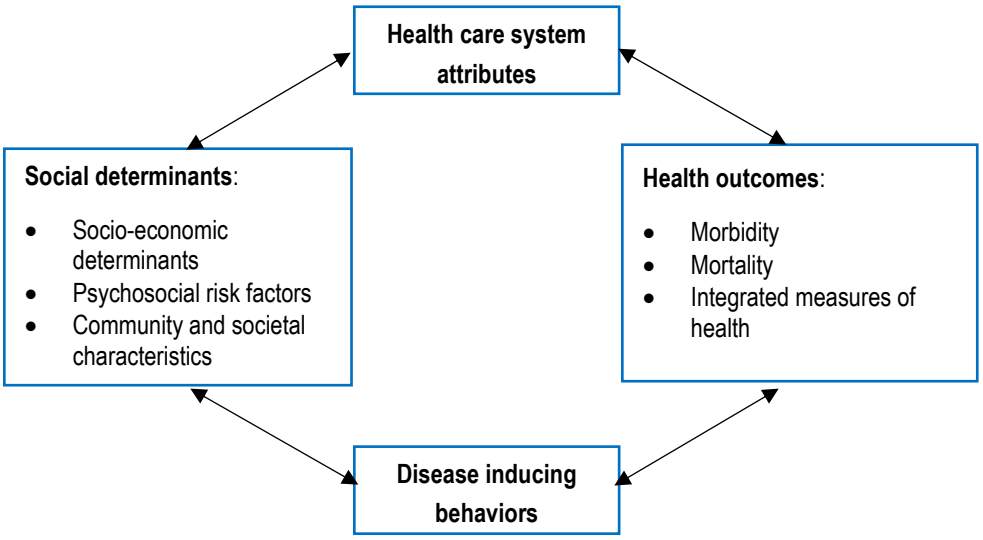
Since the present research revolves around informal care and its role in aiding mothers with schizophrenia in parenting, the information relative to the importance of context and social networks of support was especially highlighted in each section.

1.1. SOCIAL DETERMINANTS OF HEALTH AND MENTAL HEALTH

Social determinants of health, including socio-economic factors, psychosocial factors and community and societal organization, have gained strong attention in epidemiological studies in the last three decades, orienting health policy and practice worldwide (Ansari, Carson, Ackland, Vaughan, & Serraglio, 2003; Hunter & Tsey, 2003). Social determinants are considered to mutually interrelate with health care system attributes, disease inducing behaviors and health outcomes, as shown in Figure 1. Several authors have stressed their bigger influence on health and their higher power to explain the social gradient in health than individual factors (Ansari et al., 2003; Wilkinson & Marmot, 2003). Emphasis in socio-economic determinants orients action on the earliest part of causal pathways to disease, and are especially suitable to be addressed with preventive strategies at a population level (Ansari et al, 2003).

Figure 1

Public health model of the social determinants of health (Ansari et al. 2003)



Social determinants can be divided into three distinct components that are interrelated and mutually exert and influence on each other. These components are socio-economic factors, psychosocial risk factors, and community and societal factors. Some variables of these components are listed in Table 1.

Table 1

Social determinants in the public health model of the social determinants of health (Adapted from Ansari et al., 2003)

Socio-economic determinants

- Age
- Gender
- Race
- Ethnicity
- Education
- Occupation
- (Un)employment
- Income
- Religion
- Housing

Psychosocial risk factors

- Poor social networks
- Low self-esteem
- Self-efficacy
- Depression
- Anxiety
- Insecurity
- Loss of sense of control
- High physical/psychological demand
- Chronic stress
- Isolation
- Anger/hostility
- Coping
- Perception/expectations

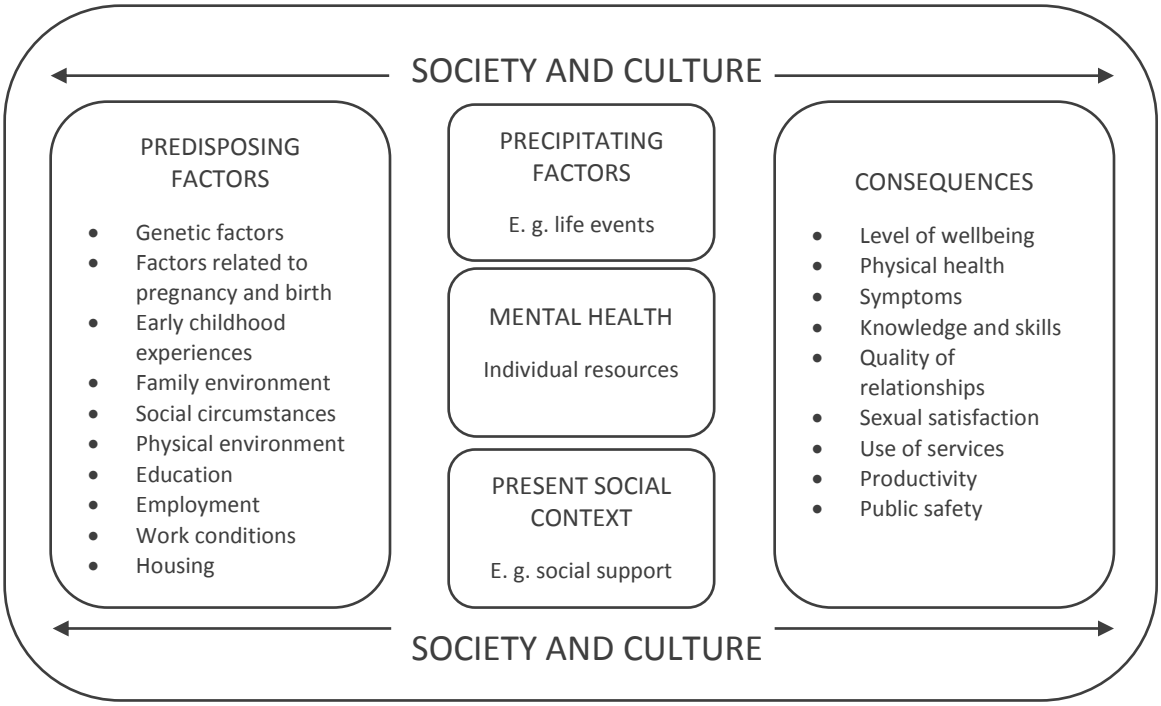
Community and societal characteristics

- Social networks and support structures
- Social and community participation
- Civic and political involvement and empowerment
- Trust in people and social institutions
- Tolerance of diversity
- Altruism. Philanthropy and voluntary work
- Poverty
- Residence (urban, rural, remote)
- Income inequality
- Crime rate
- Domestic violence
- Unemployment rate

Likewise, social determinants play an important role in mental health. According to Lavikainen, Lahtinen, and Lehtinen (2000), the determinants of mental health -considered as an indivisible part of general health- include: a) individual factors (including emotions, cognitions, actions, identity and self-esteem, autonomy, adaptive capacities, education, physical health) ; b) social support and other interactions (including family, school, work, community, etc.); c) societal structures and resources (policies, institutions, services, etc.);

and d) cultural values (prevailing societal values, stigma on mentally ill, rules regulating social interactions, etc.). As shown in Figure 2, these factors interact in a process in which some act as predisposing, precipitating and as supporting factors for several outcomes.

Figure 2
Predisposing, precipitating and supporting factors for mental health (Lavikainen et al, 2000)

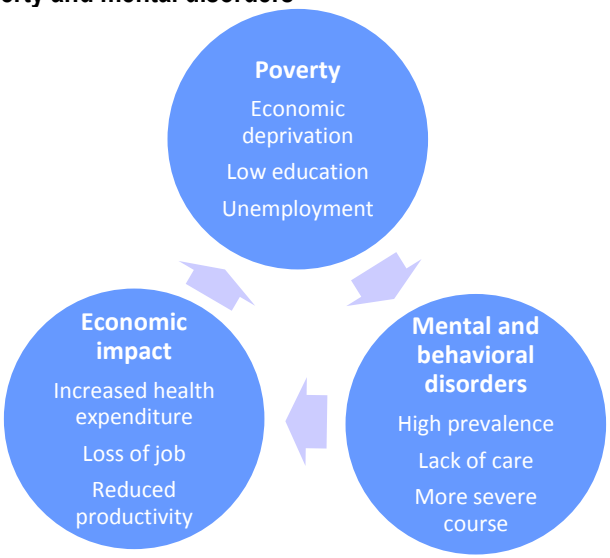


Three social determinants are considered as the main risk factors for mental disorders, namely: a) poverty and social exclusion; b) gender; and c) loss, trauma and displacement due to civil violence, war and disasters (Patel, 2007). Poverty and social exclusion include groups with poor income, low education, acute economic difficulties, debt, and difficulties to cover basic needs (Patel, 2007). Not only these factors increase the risk of poor mental health, but once the disabling effects of mental disorders appear, ability to work, to perform tasks at home and to engage in social life are negatively affected by the mental illness. As shown in Figure 3, poverty and mental illness relate in a vicious cycle in which they mutually augment each other (Patel, 2005; WHO, 2001). Additionally, poverty is associated to difficulties to access care and to a worse course of illness (Patel, 2007; WHO, 2001). Difficulties to have employment worsen the possibilities to access adequate care, especially in low and middle income countries where a high proportion of mental health care expenses are out of the pocket (Patel, 2007). Difficulties to access care affects the

course of illness, so that the course of mental disorders is also influenced by socio-economic determinants (WHO, 2001).

Figure 3

The vicious cycle of poverty and mental disorders



Adapted from: World Health Organization (2001). *The World Health Report 2001: Mental health: new understanding, new hope*. Copenhagen, Switzerland: World Health Organization.

Gender increases the risk for women to experience mental and behavioral disorders, because of the multiple roles women fulfill in society (WHO, 2001) but also because they experience disadvantages in the possibilities to control determinants of their health, like economic position and access to resources (Patel, 2007). Domestic violence and all types of violence against women have been linked to adverse mental health outcomes (Patel, 2007).

In accordance to the main determinants that affect mental health, programs to promote mental health tend to focus on advocacy for equitable socio-economic development, empowerment of women and people living in poverty, and social support (Patel, 2005). A public health approach has been considered by the WHO (2001) as the most appropriate method to reduce the burden of mental illnesses, given the extension of the problem, the multicausality of mental disorders, the extended stigmatization of the mentally ill, and the significant treatments gaps of mental illnesses. In its World Health Report (WHO, 2001), the WHO elaborated a series of recommendations to reduce the burden of mental disorders, listed in Table 2. From these recommendations, *support of a stable family life,*

social cohesion and human development are fundamental for the present study which focuses on social determinants related to social networks and support.

Table 2

Recommendations to reduce the burden of mental disorders from a public health perspective (Adapted from WHO, 2001)

- Formulating policies to improve the mental health of populations
- Assuring universal access to appropriate and cost-effective services, including mental health promotion and prevention
- Ensuring adequate care and protection of human rights for institutionalized patients
- Assessing and monitoring mental health of communities, including vulnerable populations as children, women and the elderly
- Promoting healthy lifestyles
- Supporting stable family life, social cohesion and human development
- Enhancing research into the causes of mental and behavioral disorders, the development of effective treatments, and the monitoring and evaluation of mental health systems

1.2. PARENTING AND SEVERE MENTAL ILLNESS

Even though the research was focused on women with schizophrenia and related disorders, this literature review included researches that use similar terminologies like severe mental illness and psychosis. These terms are not exact synonyms in psychiatric diagnosis, but they were included given the overlap of conditions they define, and the similarity of findings regarding these populations and their parental experiences. Findings specifically referred to schizophrenia will be clarified during the review.

This section starts with a brief presentation of the definitions and manifestations of severe mental illness and schizophrenia, to continue with the revision of several aspects related to parenting for people with SMI. These include a review of the perspectives that have guided the interventions for parents with SMI, previous evidence about common characteristics of the contexts of mothers with SMI, their strengths and difficulties in parenting, as well as existing interventions to address their needs.

1.2.1. Definition and characterization of severe mental illness and schizophrenia

The definition of SMI is broad, and groups several illnesses under the common characteristics of being non-organic and long lasting mental disorders, that produce varying degrees of dysfunction in the social, personal and labor life of the persons that

suffer from them, impeding a complete and autonomous integration to their contexts (Orihuela Villameriel, 2003; Ruggeri, Leese, Thornicroft, Bisoffi, & Tansella, 2000). The term SMI has been coined to group a series of illnesses that should be given higher priority in mental health services (Ruggeri et al., 2000) and will require more complex and intense approaches of care, related not only to health but also to social needs of patients (Orihuela Villameriel, 2003). People that suffer from a SMI tend to have a reduced quality of life, and this can be extended to their children and following generations (Bee et al., 2014). Among severe mental illnesses, schizophrenia is one of the most disabling disorders, reducing productivity and quality of life of the ill subjects and their families (Florit-Robles, 2006). According to the WHO, schizophrenia is considered one of the ten leading global causes of disability (Florit-Robles, 2006; Vermeulen et al., 2015).

Schizophrenia usually has an early onset during adolescence or early adulthood, and can have a chronic disabling course (Stefan, Travis, & Murray, 2002). Its manifestations can be grouped under three syndromes: positive, negative and disorganization syndromes. The *positive syndrome* includes symptoms of a distorted reality, like delusions, hallucinations, and passivity phenomena. The *negative syndrome* includes the so called 'deficit' symptoms like social withdrawal, apathy, flattening of affect, poverty of speech, inattentiveness. The *disorganization syndrome* includes formal thought disorders in which the normal flow of thought is disrupted, leading to thought, language and communication problems (Radanovic, de Sousa, Valiengo, Gattaz, & Forlenza, 2013: Stefan et al., 2002). Onset can be rapid or insidious, and course tends to be chronic with acute episodes. Acute episodes usually include delusions, hallucinations and passivity experiences, while the chronic illness is dominated by the appearance of negative symptoms (Stefan et al., 2002). Nonetheless, not all individuals undergo a chronic course and recovery has been described in up to 20-30% of cases (Hopper et al., 2007; Saha et al., 2005).

Schizophrenia causes severe anguish and varying degrees of cognitive, affective and psychosocial impairment, despite treatment (Sadock & Sadock, 2000; Stefan et al., 2000). As well, it is associated with reduced productivity and quality of life, and has a great social and economic impact for the sufferer and their families (Florit Robles, 2006; Stefan et al., 2002). Its early onset and chronic course in approximately two-thirds of affected individuals are the main features associated to its burden of disease (Saha et al., 2005). Its disabling character turns schizophrenia into a major public health problem (Hopper, 2007), even when it has a low prevalence. Prevalence of schizophrenia shows substantial variation

between sites and according to the criteria used to define it, and in general ranges between 0.4 to 1 percent of the population (Sadock & Sadock, 2000; Saha et al., 2005; Stefan et al., 2002).

1.2.2. Perspectives that guided the interventions for families in which the mother has a SMI

Until the middle of the 20th century, the possibilities of mothering for women with SMI were denied through long-term institutionalization, prohibition of marriage and compulsory sterilization. Prohibition of marriage and sterilization required by law on women with diagnoses of schizophrenia and 'manic-depressive lunacy' among others, were part of eugenic policies implemented during the 19th and 20th centuries in many European countries (Krumm & Becker, 2006). Life stories of people with mental illness in western countries started to change during the middle of the 20th century, when psychiatric reforms were implemented in several western countries. These reforms, which started during the 1950s and 1960s, introduced a radical change in the way of conceiving mental illness, the person suffering from a mental illness, their rights and the care they should receive. Cornerstones of the psychiatric reform included deinstitutionalization and care based in the community (Torrez-Gonzalez, 2011). Emphasis was put on strengths and resources rather than on deficits, allowing the person to exercise their autonomy and self-determination in the planning of their life paths. The change of paradigm broadened the opportunities for many people with SMI to live 'normal' lives, find partners and exercise their reproductive and parenting rights (Krumm & Becker, 2006; Mowbray, Oyserman, & Ross, 1995). Deinstitutionalization could partly explain the raise of fertility rates of women with schizophrenia that was described in the last decades, still remaining lower than in general population (Dickerson et al., 2004; Nimgaonkar, Ward, Agarde, Weston, & Ganguli, 1997; Vigod et al., 2012).

In the last decades, the ways to approach parenthood in the context of serious mental illness have also shifted from a negative, deficit oriented to a more comprehensive perspective. Until the early 1990s researchers focused mainly on the negative consequences for children of being raised by a mentally ill parent. After that, researchers have introduced a resource-oriented perspective with greater concern for the subjective views of mothers, including negative and positive aspects, and the need of adequate support to improve quality of life and outcomes (Krumm & Becker, 2006). Both

perspectives will be briefly revised in the following lines, followed by a short review of the evidences that support the resource-oriented perspective.

a. The 'risk' perspective

This perspective focuses on deficits and abnormalities in parenting behaviors of people with SMI and the consequences of genetic and environmental risk for children of mentally ill persons. Interventions based on the perspective of risk tend to have the primary aim to 'protect' the child from the risky mother by measures of surveillance and termination of parental rights when a problem arises, based on unclear and many times biased parameters to evaluate parental competency (Ackerson, 2003). Indeed, it is frequent that mothers with schizophrenia are contacted by child social services, have their children under child protection systems and lose custody of their children, sometimes immediately after birth (Dipple, Smith, Andrews, & Evans, 2002; Gearing et al., 2012; Irving & Saylan, 2007; Westad & McConnell, 2012). It is worth noticing that the risk of developing a psychopathological disorder can be heightened when children are separated from their parents with severe mental illness, putting in question the effectiveness of the above-mentioned measures (Duncan & Browning, 2009; Oyserman, Mowbray, Meares, & Firminger, 2000).

b. The resource-oriented perspective

Several authors as Hearle and McGrath (2000) and Phyllis Montgomery (2005) have criticized the limited focus on children and the overstated view of risk that led to a conception of parents as 'toxic or dangerous' for their children. They note that exclusive focus on negative aspects reaffirms the marginalization of the mother undermining her confidence and possibility of agency and at the same time placing responsibility on child outcomes only on her. Moreover, such a focus fails to address the ethical responsibility of society and health care providers to open alternatives for support without threat or harm.

Support for a more positive view of parenting in people with SMI was given by authors like Pawlby et al. (2010) who intended to find flaws in the studies based on risk. These include the absence of clear mechanisms that link parental mental illness and disturbances in child development, and the failure to systematically replicate the described negative mother-child interactions. Contradicting previous descriptions of negative mother-child interactions, Mowbray et al. (1995) showed adequate and mature parenting attitudes in mothers with SMI, Perera et al. (2014) found mothers had strong feelings of love for their children, and Ackerson (2003) found that many parents with SMI do not show

dysfunctional parenting behaviors but strong and close relationship with their children. The study of Savvidou et al. (2003) also demonstrated that most women with SMI could realize and describe the needs of their children, describe own difficulties in child rearing and give a consistent and coherent narrative of their children. As well, other authors demonstrated that many mothers expressed worries and hopes about children in the future (Bonfils et al., 2014), wanting to keep their children safe, happy (Perera et al., 2014), and wishing they would have 'normal' lives (Nicholson, Sweeney, & Geller, 1998a).

Other groups have focused on factors that could have a greater influence on parenting and child outcomes than the presence of the illness itself., including characteristics of the context and past and present life situations (Oyserman et al, 2000).

This is why many authors give higher priority to functional and contextual evaluations than to a specific diagnosis when parenting abilities are being assessed and give high value to interventions that address the contextual needs of women and allow them to develop stronger parental competencies with the support of their partners, families and health care services (Ackerson, 2003; Benjet, Azar, & Kuersten-Hogan, 2003; Montgomery, Tompkins, Forchuk, & French, 2006; Oyserman et al., 2000; Reupert & Maybery 2007; Seeman, 2013).

1.2.3. Frequent contextual characteristics among parents with severe mental illness

Parents with a severe mental illness tend to present more unfavorable contextual aspects than parents without illness (Barkla & McGrath, 2000; Bee et al., 2014, Montgomery et al., 2006). They are more frequently exposed to economic problems, poverty (Fraser, James, Anderson, Lloyd & Judd, 2006; Perera et al., 2014), poor housing (Bee et al., 2014; Fraser et al, 2006; Montgomery et al., 2006; Perera et al., 2014) and tend to have low educational background (Bee et al., 2014). As well, women with SMI tend to show difficulties in building and maintaining social networks, experience difficult relationship with their families (Bee et al., 2014), lack partner (Nicholson, Biebel, Hinden, Henry, & Stier, 2001; Perera et al., 2014), lack social support (Barkla & McGrath, 2000; Montgomery et al., 2006) and raise their children in solitude (Hearle & McGrath, 2000; Nicholson, Sweeney, & Geller, 1998b; Zemencuck, Rogosch, & Mowbray, 1995). They were also found to be at higher risk of experiencing violence during pregnancy (Miller & Finnerty, 1996) and of losing custody of children (Ackerson, 2003; Perera et al, 2014). All these factors account for mothers with SMI to be considered as one of the most vulnerable groups in society (Bee et al., 2014).

Furthermore, they are frequently excluded from health and social care, and it is common that their needs as parents are not taken into account in mental health care programs (Bee et al., 2014; Duncan & Browning, 2009).

Within the group of individuals with SMI, mothers with schizophrenia tend to show more complex clinical and psychosocial problems, and poorer parenting outcomes than mothers with other SMIs (Abel, Webb, Salmon, Wan & Appleby, 2005; Howard et al., 2004).; Howard et al., 2004). They present more economic difficulties, poorer quality of relationships, poorer networks of support, being more frequently exposed to violence during pregnancy, and more frequently having a partner with psychiatric illness (Abel et al, 2005; Miller & Finnerty, 1996). They also tend to be separated from the partner when the child is born (Hearle & McGrath, 2000; Mowbray et al., 1995; Nicholson, 1998b).

1.2.4. The experiences of parenting in women with severe mental illness, including schizophrenia

A common finding in researches that explored the experiences of motherhood in women with SMI is the high value and importance they place on motherhood (Diaz-Caneja & Johnson, 2004; Dolman et al., 2013; Montgomery, 2005; Mowbray et al., 1995; Perera et al, 2014; Reupert & Maybery, 2007; Savvidou et al., 2003). Various researchers found that in general these mothers have strong positive views about motherhood and consider children as a source of joy and satisfaction (Savvidou et al., 2003). Having children was a central experience (Diaz-Caneja & Johnson, 2004; Dolman et al., 2013) in life, a source of personal growth and fulfillment which gave their lives an identity, a meaning and purpose (Mowbray et al., 1995; Mowbray, Oyserman, Bybee, MacFarlane, & Rueda-Riedle, 2001; Perera et al., 2014). Maternity as well implied the possibility of feeling responsibility while they obtained recognition and support (Diaz-Caneja & Johnson, 2004; Montgomery et al., 2006), and was considered by many as a normalizing experience (Perera et al., 2014; Nicholson et al., 1998a). “Normality” can be highly valued by people with mental disorders, and motherhood and family life could represent a highly-valued way of reproducing normality (Krumm & Becker, 2006).

Nevertheless, mothers with schizophrenia and other SMI tend to show difficulties in parenting with higher frequency than other groups of parents. They have been described to have a higher risk of inappropriate behaviors in the interaction with their children, like being less sensitive, vigorous and communicative, or excessively demanding and intrusive

with their children (Gearing et al., 2012; Howard et al., 2004; Snellen, Mack, & Trauer, 1999). They have been frequently described as distant (Perera et al, 2014), less emotionally available (Bee et al., 2014) and experiencing difficulties with attachment (Bee et al., 2014; Duncan & Browning 2009; Riordan, Appleby, & Faragher, 1999). Discipline and control of children behavior is another domain were mothers with SMI tend to present difficulties, with a tendency to show over-permissive attitudes (Gelkopf & Jabotaro, 2012; Nicholson et al., 1998a; Oyserman, Bybee, Mowbray, & Hart-Johnson, 2005; Perera et al., 2014). Difficulties in recognizing the child´s needs and respond to them (Brunette & Dean, 2002; Wan et al., 2007), negligent attitudes (Duncan & Browning, 2009), as well as stimulation of poorer quality (Bee et al., 2014) have been frequently reported. Difficulties in parenting seem to be more frequent in women with schizophrenia when compared to other SMIs, with a three times higher risk of poor parenting outcomes after a hospitalization (Abel et al., 2005). Poorer outcomes include more difficulties in emotional responses to their children, less engagement with their children, more difficulties in caring for their children, and higher risk of having children under supervision or being separated from them (Abel et al, 2005; Howard et al., 2004; Murray, Cooper, & Hipwell, 2003). Women with schizophrenia have an additional disadvantage since they tend to take longer times to fully recover (Hammond & Lipsedge, 2015).

Lack of insight of own difficulties in parenting has been mentioned by some authors (Duncan & Browning, 2009) but also a tendency to experience feelings of failure, shame, guilt and low self-esteem, especially when difficulties in parenting were evident (Dolman, 2013; Perera et al, 2014; Power et al., 2011), or when mothers had to give up parenting, even temporarily (Davies & Allen, 2007). Mothering in the context of mental illness created a pressure for mothers to conceal the identities of motherhood and mental illness and deal with them simultaneously, leading to extenuating efforts specially when women try to adequate themselves to the dominant image of a 'good mother' (Bee et al., 2014; Davies & Allen, 2007; Diaz-Caneja & Johnson, 2004; Montgomery, 2005; Perera et al, 2014; Power et al., 2011).

The exact mechanisms through which these difficulties and mental illness are related are not clear. Several authors have proposed that positive and negative symptoms (Snellen et al, 1999) can influence the attitudes of mothers with SMIs and cause difficulties in parenting. In some studies, mothers identified the symptoms of illness that resulted more disruptive for parenting, including anxiety, irritability, hallucinations and delusions. Children

can be involved in psychotic symptomatology of mothers (Fraser et al., 2006), which can result in the mother distancing and detaching from the child (Perera et al., 2014). Also, adverse effects of medication, especially sedation and slow thinking, were considered as major disruptors for mothering tasks (Diaz-Caneja & Johnson, 2004; Savvidou et al., 2003). Lack of insight (Duncan & Browning, 2009) and lack of confidence (Oyserman et al., 2005; Perera et al., 2014) can affect maternal attitudes and cause difficulties in parenting as well.

Factors beyond the presence of symptoms of mental illness have shown a greater influence on mother-child interactions, including age of onset and premorbid functioning (Abel et al., 2005), past and present experiences of abuse and neglect, and characteristics of the context and life situation (Abel et al., 2005; Gearing et al., 2012; Howard et al., 2004; Nicholson et al., 1998b; Oyserman et al, 2000).

Contextual characteristics with the highest impact on mother-child interactions include the presence of socio-economic problems (Abel et al., 2005; Gearing et al., 2012), having poor social support or conflicts with networks of support (Abel et al., 2005; Brunette & Dean, 2002; Nicholson et al., 1998b), being single, having a poor relationship with partner, or having a partner with psychiatric illness (Abel et al., 2005; Howard et al., 2004). Additionally, mothers frequently reported a negative influence of experienced stigma on parenting. They frequently felt under surveillance, moral judgment and denial of their competence and expertise (Davies & Allen, 2007). Several researchers showed that mothers felt people had negative assumptions about parents with mental illness, assuming they would be bad parents (Perera et al., 2014). Stigma can be internalized and cause women to define themselves from a deficit-based perspective, reducing their confidence and effectiveness (Dolman et al., 2013; Perera et al., 2014; Savvidou et al., 2003). As well, stigma was associated with additional stress on child caring, fear of being negatively judged as a mother (Perera et al., 2014), need of constantly prove themselves in the eyes of others (Nicholson, 1998a), difficulties in openly talk about their problems and fear of discrimination falling on their children (Diaz-Caneja & Johnson, 2004; Perera et al., 2014). As a result, mothers tended to reduce their participation in social activities and had difficulties in finding appropriate and consistent support from the community (Diaz-Caneja & Johnson, 2004). Social isolation and discrimination, and reduced social capital could in fact compromise parenting (Bee et al., 2014) and create a difficult situation to the mentally ill parents and their children, acting like a self-achieved prophecy.

On the other side, contextual factors have showed to be beneficial for parenting and protective for the child's development when a parent has a SMI, including access to social and economic resources, positive social networks, family stability, good relationships between parents and child, and having a partner without mental illness that is highly involved in childcare (Abel et al., 2005; Gearing et al., 2012).

1.2.5. Influences of maternity on mother's evolution and wellbeing

For individuals with SMI, being a parent can be a motivation to socialize and be involved in social activities (Mowbray et al., 2001) with positive impact on their lives. It can also have a positive impact on their mood, mental health and general health, sine mothers tend to find in their children a motivation to keep stable, maintain treatment and be more careful healthy habits in general (Diaz-Caneja & Johnson, 2004; Mowbray et al., 2001; Perera et al, 2014; Reupert & Maybery, 2007).

But having children can also affect the mother's wellbeing and evolution in a negative way. Several mothers with SMI expressed concerns that are common to many other groups of mothers, like feeling overloaded with activities and experiencing limitations in freedom, lacking time for themselves and having less working and studying opportunities (Mowbray et al., 2001). Additionally, demands and challenges of parenting can be a source of stress (Perera et al., 2014), irritability and anxiety (Mowbray et al., 2001) which can affect their evolution, and having to take care of children was also considered as a limitation to receive appropriate health care for many mothers. Several authors have showed that mothers frequently worry about who would take care of their children in case they have a relapse and do not look for care until they achieve a critical point (Dipple et al., 2002; Nicholson et al., 1998a; Perera et al., 2014). Others are reluctant to take medication because of the adverse effects that can difficult their parenting (Diaz-Caneja & Johnson, 2004; Nicholson et al., 1998a). Another limitation in care was expressed by many mothers that did not get hospitalized even when needed because they needed to take care of their children (Montgomery et al., 2006; Nicholson et al., 1998a, Perera et al., 2014). Fear of losing custody was a constant finding in all studies and pervaded all interaction with health and welfare services (Diaz-Caneja & Johnson, 2004; Perera et al., 2014), and many mothers avoided contact with mental health services because they feared children could be taken away (Perera et al., 2014). In fact, mothers with SMI and their children are frequently involved with social services, and with higher frequency have their children in foster care than mothers without SMI (Bee et al., 2014). Another common concern was the

fear of children becoming mentally ill or having developmental problems, because of biological risk, environmental factors or discriminative social attitudes and isolation (Diaz-Caneja & Johnson, 2004; Dolman et al., 2013; Perera et al., 2014).

1.2.6. Consequences of parental mental illness on children

Children of parents with SMI frequently experience consequences of the parental illness in their own health and development. According to van Santvoort et al. (2015), approximately one third of these children show transient mental problems, and another third experience more serious and long-term consequences. Children of mentally ill parents, when compared to children of parents without mental illness, are at higher risk of abuse and neglect, attachment problems, disturbed emotional, social and cognitive development, and poorer general and mental health (Duncan & Browning, 2009; Henriksson & McNeil, 2004; Reupert & Maybery, 2007; van Santvoort et al., 2015). Among others, these children present increased rates of delayed walking, enuresis, behavioral and language disturbances (Henriksson & McNeil, 2004), academic problems (Stefan et al., 2002), poorer general health (Reupert & Maybery, 2007), and psychological disorders during childhood, adolescence and adulthood (Phelan, Lee, Howe, & Walter, 2006; Perera et al., 2014). Children can show the same disorder than their parents, but also a broader spectrum of problems (van Santvoort et al., 2015). The risk of developing psychopathology is increased two to thirteen times, including pathologies as depression, anxiety disorders, suicidal behavior, substance abuse and eating disorders (van Santvoort et al., 2015). Children of parents with schizophrenia are particularly vulnerable to all the described consequences, including a higher risk of poor emotional, behavioral and cognitive outcomes, and psychiatric symptoms in adulthood (Abel et al., 2005).

An interplay of genetic, neurobiological and environmental mechanisms has been proposed to cause the negative outcomes in children (Reupert & Maybery, 2007; van Santvoort et al., 2015), but no clear mechanisms have been established to link the parental mental illness and the disturbed child development (Pawlby et al., 2010). Some authors have proposed quality of parent-child interaction, quality of attachment and parental resilience as probable mechanisms that influence children's difficulties in socio-emotional adjustment of children and the appearance of disturbances in their development (Bee et al., 2014; Stefan et al., 2002). Additionally, children can experience distress, disruption and feelings of loss during hospitalization of their parents (Maybery, Reupert, Patrick, Goodyear, & Crase, 2005), which can as well affect their development.

Psychosocial risk factors associated to mental illness can cause problems in children as well, beyond parent's behavior, cognition and emotions (van Santvoort et al., 2015). Some studies have tried to identify which of these factors are more powerful in predicting child outcomes, but findings until now have not been consistent. Severity and chronicity of parental illness were identified by some authors in this respect (van Santvoort et al., 2015), while others have stressed contextual aspects like the presence of social support (Howard et al., 2004; Mitchell, 2004).

A special situation is the one of children acting as carers of their mentally ill parents. To be considered as a 'young carer', children under 18 years of age need to provide significant or substantial care, assistance or support, with responsibilities that would be normally associated with an adult (Mitchell, 2004). There are not many reports on the proportion of children that act as carers. Aldridge and Becker (2003) have calculated that the chance of having cared for a parent in childhood was of 1.3% among the young population in the UK. Children undertake diverse caring tasks, especially emotional support, but also assistance of crisis, watching on parent's wellbeing, supervision or administration of medication, domestic tasks and household management (Aldridge, 2006; Aldridge & Becker, 2003). Consequences on children who act as carers include less opportunities to socialize with other children and poor performance at school, but also positive consequences like strengthening bonds between the ill parent and the child and feel the child feel included in a context that is often discriminative (Aldridge, 2006; Aldridge & Becker, 2006). Authors have described a risk for child's development when the caring role is assumed in the long-term, and when responsibilities are disproportionate to their age or maturity (Aldridge, 2006). Interestingly, long term and disproportionate care have been described more frequently when the child is a girl, when the ill parent is a mother, who is a lonely parent and has no paid work (Aldridge, 2006; Aldridge & Becker, 2003). The same authors have found that children tend to be involved in continuous care because they can provide immediate, flexible, consistent and long-term care at home. This unmasks a deficit in the parent's context and in professional care, both of which fail to cover support needs of parents (Aldridge, 2006). In fact, children acting as long-term carers can be a sign of individual professional responses that fail to consider families' experiences and needs, with narrow focus on medical and adult problematics, and a rigid division between adult and children's services (Aldridge, 2006; Mitchell, 2004).

1.2.7. Interventions to address parenting difficulties in parents with SMI

Few specialized psychosocial treatments exist that address mothers with schizophrenia and related disorders and their unique parenting needs (Ackerson, 2003; Gearing et al., 2012; Mordoch & Hall, 2002). In the last three decades, some programs have been developed but in general have lacked funding and systematic integration into policy. As well, empirical evaluations are scarce (Mordoch & Hall, 2002).

Based on the different mechanisms postulated to explain the links between mental illness, parenting difficulties and children outcomes, preventive interventions that address these mechanisms have been proposed to improve parenting and children outcomes in families in which a parent has a SMI. Interventions can address different stages of parenthood, from pregnancy to later periods of child development, and target one or more of the following focuses of action: a) achieving and maintaining psychiatric stability; b) support in parenting abilities; c) direct support for the child; d) interventions on social networks of support; and e) interventions on the societal level. These areas of intervention will be briefly described in the following lines, dedicating a special section to the theme of this research, social support for mothers with SMI.

a. Achieving and maintaining psychiatric stability:

Given the high risk of psychotic relapses during pregnancy and postpartum, and the higher risk of obstetric complications described in schizophrenic patients, some groups have designed a series of interventions with the aim to maintain psychiatric stability and general health of mothers with schizophrenia during pregnancy and postpartum.

Seeman (2008, 2013) and Nishizawa, Sakumoto, Hiramatsu, and Kondo (2007) propose a series of interventions on pregnant and postpartum women to address risk factors of negative outcomes in their offspring. These include nutritional assessments, fitness programs, education and prevention of maternal infections during pregnancy, substance abuse programs, careful and individualized psychotropic treatment, education on self-monitoring symptoms and early consultation in case of relapse, assessment and intervention in case of domestic abuse, organization of family support and of proper housing, and preparation of finances and healthcare before the child is born. The higher risk of postpartum psychosis requires prevention through adequate pharmacotherapy, and preparation through education of the mother and her family beforehand, including identification of symptoms and management of crisis. Unfortunately, little evidence has

been collected regarding the effectiveness of these interventions. Nishizawa et al. (2007) demonstrated symptomatic and functioning improvement through the administration of medication without interruptions and at minimal doses, and varied types of nun-drug-related support during pregnancy and postpartum.

A special unit of intervention in case mothers need hospital psychiatric admission within the first year of childbirth are Mother Baby Units. These Units jointly admit mothers with their children so to protect their bonding. Few researches have been performed to confirm their effectiveness, but some studies have found good outcomes in terms of parenting and symptoms management after admission. Nevertheless, mother-baby units have not shown effectiveness in reducing long term risks, probably because no continued parental assistance is offered (Gearing et al., 2012; Howard et al., 2004; Irving & Saylan, 2007).

Psychiatric stability and preservation of general health have also been proposed during later periods as interventions to improve parenting. Seeman (2013) proposes that health care teams assist mothers with schizophrenia to look after their own health, recognize signs of relapse and look for help, in order to prevent custody loss and negative parenting and child outcomes. Improvement of psychopathological symptoms have shown to be associated to increased nurturance in parents (Kahng, Oyserman, Bybee, & Mowbray, 2008; Seeman, 2013). However, the same authors have demonstrated that an improvement of symptoms is not enough to improve parenting completely, since other factors like contextual risk need to be addressed too (Kahng et al., 2008).

b. Support for the mother regarding parenting abilities:

Specific guidance in parenting abilities can be provided to mothers in different ways. Parenting capacities can be evaluated informally during regular consultations. Special attention should be payed to mother´s symptoms, ability to learn, practice of safe infant care, children´s difficulties, type of disciplinary methods, and availability of support (Seeman, 2013). Professionals can help parents to identify problems in the interaction and communication with children, to identify needs of more information, to set goals, to develop parenting skills and provide feedback of observed interactions with the child (Brunette & Dean, 2002).

The problem is that interventions that have shown effectiveness in parents with other mental illnesses, especially depression, or other vulnerable situations, cannot be necessarily replicated or extrapolated to women with schizophrenia (Ackerson, 2003; Seeman, 2013). The most effective interventions for parents with schizophrenia appear to

be didactic parenting classes, skills training, development education, and time-limited co-parenting support according to recent reviews (Gearing et al., 2012; Seeman, 2013). Interventions that address parents and children simultaneously and showed to be effective include directed play, role modeling and language development. These interventions showed an improvement in parenting skills and in mother-child interaction (Gearing et al., 2012).

Parents with schizophrenia might show difficulties to receive some types of intervention, like video-based feedback to improve maternal sensitivity. This has proven to be effective in depressed mothers (Wan, Penketh, Salmon, & Abel, 2008), but there is no evidence of efficacy in psychotic mothers. Caution in their use is advised wince they might be emotionally challenging intervention, with the risk of increasing anxiety levels and worsen existent difficulties in parenting. These interventions might also not be feasible in psychotic mothers who show cognitive biases and paranoid tendencies. Moreover, authors like Guttentag, Pedrosa-Josic, Landry, Smith and Swank (2006) have found that maternal sensitivity and interactions are difficult to change in mothers who lack support. Having adequate support seems then to be a prerequisite before trying to improve their emotional resources.

Limitations in interventions are also caused by the fear of parents with schizophrenia to be judged negatively, stigmatized, or have their children taken away (Gearing et al., 2012). These might limit participation in group dynamics, or directly hinder parents to look for help. Treatment along with their children, and receiving interventions that address parenting within services they already visit have proven to be better accepted and effective for this population (Gearing et al., 2012).

In conclusion, several authors have recommended a personalized approach to parents with schizophrenia, within a multi-level support that starts in pregnancy and will gradually focus on parenting capacities (Wan et al., 2008). It is also important to organize a crisis plan in case the mother is temporarily impaired to take proper care of her children (Seeman, 2013), to address other needs of families like financial support, and especially to strengthen networks of support to ensure the effectiveness of any intervention (Gearing et al., 2012).

c. Direct support for the child

Children's wellbeing is one of the most important concerns that motivate the development of interventions for mentally ill parents. In this way, all the described interventions have the

aim of improving children's outcomes, but most of them do not directly involve children nor include them directly in preventive strategies. Several authors have observed that needs of children of parents with SMI tend to be overlooked, and no response for them is given by adult mental health care services (Orel, Groves, & Shannon, 2003; Pitman & Matthey, 2004; Reupert & Maybery, 2009).

Children can be involved in mutual treatment programs with parents, but also be specifically targeted in programs for children of parents with SMI. Programs implemented in this area attain multiple goals, including monitoring of children's development and provision of early intervention if required (Brockington et al., 2011; Gearing et al., 2012; Valenzuela Soler et al., 2009). Even when no emotional or developmental consequences are observed, interventions can address needs of children associated to their feelings and experiences of having a parent with SMI. These include reducing social isolation (Mordoch & Hall, 2002; Pitman & Matthey, 2004; Reupert & Maybery, 2009), fostering peer support and networking (Reupert & Maybery, 2009), educating children about the parental mental illness so to promote the understanding of the mentally ill parent and learn about management of crisis (Brockington et al., 2011; Mordoch & Hall, 2002; Orel et al., 2003; Pitman & Matthey, 2004; Reupert & Maybery, 2009;), organizing activities to have fun and respites from care (Reupert & Maybery, 2009), building resilience and coping capacities (Orel et al., 2003; Pitman & Matthey, 2004; Reupert & Maybery, 2009), assisting in problem solving (Mordoch & Hall, 2002; Reupert & Maybery, 2007); improving the ability to cope with feelings related to having a parent with a SMI (Orel et al., 2003); improving confidence, self-esteem, self-expression and creativity (Mordoch & Hall, 2002; Orel et al., 2003; Pitman & Matthey, 2004; Reupert & Maybery, 2009), improving parent-child relationship (Pitman & Matthey, 2004), providing support to the child (Pitman & Matthey, 2004), strengthening available systems of support (Orel et al., 2003), and contact with other agencies (Brockington et al., 2011).

To achieve these goals, some programs have organized interventions of brief duration that provide peer support, psychoeducation, and structured activities to have fun, improve communication of feelings and learn life skills associated to coping abilities and resilience (Orel et al., 2003; Pitman & Matthey, 2004; Reupert & Maybery, 2009). Other programs have organized a follow up of all children of parents with SMI, through regular contacts with family doctor, pediatrician, schools, and regular interviews with parents. Controls of adequate general health status, vaccinations, schooling and care at home are performed

during follow ups, and early and adequate intervention is guaranteed if needed (Valenzuela Soler et al., 2009). In this way, the development of adequate child and adolescent mental health services seems to be essential for the promotion of mental health in vulnerable children (Brockington et al., 2011).

d. Interventions on social networks of support, community and society

Several authors have suggested the need of mental health settings and social services can involve the whole family in care, so to improve the quality of relationships and support within the family (Colina, 2003; Nicholson et al., 1998b). Supporters might need education about mental illness, education and clarification of their role, and might need support for themselves to avoid feelings of burden, exhaustion, conflicting functioning, and keep the support network intact (Hearle & McGrath, 2000; Nicholson et al., 1998b; Reupert & Maybery, 2007).

Mobilization of community resources has been strongly recommended, including contact of parents and caregivers with their respective support groups, parenting classes, churches and neighborhood associations (Brunette & Dean 2002). Formal support can be sought through the legal and welfare system, as well as from child care services if needed (Brunette & Dean, 2002; Seeman, 2013).

Given the frequent situation of socio-economic deprivation, unemployment and social exclusion, these aspects could be tackled by social services or specific services to provide financial assistance, housing, transportation, and promote social inclusion. These aids would promote independency, adequate family functioning and freedom of discrimination for people with mental illnesses (Brunette & Dean, 2002; Reupert & Maybery, 2007; Seeman, 2013).

Specific programs against stigma have been proposed to encourage respect and inclusion of families in which a parent has a severe mental illness (Reupert & Maybery, 2007). Compatibility between motherhood and mental illness can be demonstrated through arrangements in mental health care facilities that intend to maintain parental roles during mental health care, like the provision of family-friendly waiting areas, child-friendly toilets, etc. (Davies & Allen, 2007). Additionally, mental health professionals can reconcile the identities of mother and mentally ill when interacting with other professionals and family members (Davies & Allen, 2007).

1.3. SOCIAL SUPPORT AS A RESOURCE OF CARE

Social relationships and the support they provided have shown significant links with health outcomes. Social support is a multidimensional concept that refers to helpful functions and provision of psychological and material resources provided to an individual by informal or formal sources, including family members, friends, co-workers, relatives, neighbors, church and health care institutions among others (Beeber & Canuso, 2005; Cohen, 2004; Thoits, 1985). The quantity of social relationships, the structure of an individual's social network, the support received by it, as well as the quality of the interactions, have been identified as predictors of health and wellbeing. They affect general health, psychological wellbeing, health behaviors and mortality risk (Cohen, 2004; Umberson, & Karas, 2010). Social support has also shown to have important links with parenting behaviors and outcomes. In this way, it is considered as a resource of aid for vulnerable families and parents with difficulties in parenting, or an area to intervene in case of an unfavorable social context (Beeber & Canuso, 2005).

Worth noticing is that correlations between support and health outcomes have shown strong evidence in studies with natural social networks. Studies to address the effectiveness of social interventions have been mainly performed with support provided by strangers, and shown less impressive results (Cohen, 2004). On this basis, some authors recommend broadening the view of interventions on social support, including interventions on natural networks. These would consist of strengthening natural social networks, increasing the support coming from them, and reducing negative interactions within these networks (Cohen, 2004). To develop this kind of interventions, more research is needed into which aspects of support are supportive, through which mechanisms, and from whom and in which conditions it would be beneficial or harmful (Thoits, 1985).

1.3.1. Functions and mechanisms to explain the effects of social support

Social support can be classified into different types in accordance with the functions performed by supporters, namely socio-emotional, instrumental, and informational. Socio-emotional functions include demonstration of affection, assertions, caring, empathic relationships, sympathy, validation, trust, and provides the opportunity to express emotional aspects (Beeber & Canuso, 2005; Cohen, 2004; Thoits, 1985). Instrumental aids include material aids related to ordinary responsibilities, like household tasks, childcaring tasks, financial support (Cohen, 2004; Thoits, 1985). Finally, informational aid

includes relevant information, advices, orientation about how to deal with current difficulties, like searching for a job or medical care, or how to improve life circumstances (Cohen, 2004; Thoits, 1985).

Social networks and the support they provide have shown beneficial impacts on health and psychological wellbeing, existing a graded relation between social integration and health (Cohen, 2004). Two generic mechanism have been proposed to explain the impact of support on health and psychological wellbeing: a buffering of stress and main direct effects, both of which would account for the beneficial effects of support. Given the influence of stress on health and wellbeing, social support can reduce the impacts of the exposure to negative life events, by providing necessary psychological and material resources to cope with stress (Cohen, 2004; Thoits, 1985). This is the buffering mechanism, which would operate for people facing an adversity, but not for people without highly stressful difficulties. The perception of available support can already act as a stress buffer, by improving the appraisal of the situation and the ability to cope with demands (Cohen, 2004). Besides, the actual provision of support can buffer stress by solving the problem, distracting from it or reducing the perceived importance of the problem (Cohen, 2004).

But social support has direct effects on health as well, irrespective of the presence or absence of stress. Social networks might influence health behaviors by peer pressure or provision of information, might increase motivation to take care of one self when feeling responsibility towards others, can affect the sense of self and emotional regulation, and can also provide aid to improve the use of health services (Cohen, 2004).

Opposite situations, like being socially isolated and lacking support, make the person more vulnerable to stress but can act as stressors themselves, having a negative impact on health and wellbeing. On the other side, social networks can be an origin of conflict, stress and loss, all of which can act as stressors which can also increase the risk of poor health (Beeber & Canuso, 2005; Cohen, 2004).

1.3.2. Social support for individuals with severe mental illness

The role of families and communities drastically changed after the psychiatric reforms. Within traditional institutional psychiatry, the mentally ill were isolated so to protect their families and communities, and sometimes also to protect the mentally ill individual from pernicious influences of their close environment (Mello, 2005).

When reforms were introduced, the role of families and communities in care was modified. Community mental health prioritizes preventive interventions and support in daily lives, addressing not only needs derived from the psychopathological manifestations, but also social, affective and existential needs (Torres-Gonzalez, 2012b). This approach is based on the recognition of the subjectivity of the consultants and their experiences, with emphasis on their autonomy, communication and participation in their care (Mello, 2005). As well, emphasis is given to the social dimension of illness, with dynamic valuations of the context in which the mental health problematic appears, so to recognize available resources to provide support (Krumm & Becker, 2006; Novella, 2008; Torres-González, 2012b). Mental health care is provided within the community, with strong focus on prevention, rehabilitation and social integration of the mentally ill (Novella, 2008).

Social networks and the support they provide have been legitimized in the community oriented paradigms of mental health care as an important resource for care of people with SMI, especially valuable to improve care in daily life and integrated in the community (Antonioli, 2011; Krumm & Becker, 2006; Torres-González, 2012b). In this context, the term ‘non-formal’ or ‘informal’ care has been coined as a way to praise the value of social support as part of care, while differentiating it from formal, professional sources of care. This term refers to non-professional care provided by someone from the social environment, without formal organization and involving an affective quality (Antonioli, 2011; Colina, 2003; Van den Berg, Brouwer, & Koopmanschap, 2004; Wright, 1987).

Informal care is a heterogeneous activity and therefore can be defined in various forms. Common aspects mentioned in several works about informal care are (Antonioli, 2011; Colina, 2003; Van den Berg et al., 2004; Wright, 1987): a) the provision of care for dependent people by somebody from the social environment of the recipient that has a previous relationship with her, generally relatives and friends and generally women; b) the lack of formal organization of the care provided; and c) the lack of payment. If paid, the provider receives less than full wage or would not provide that care for somebody outside his social environment. Activities and tasks of informal care can involve personal care, home keeping, provision of medicines, nursing tasks, mobility inside and outside the home, administrative tasks, mediation in the communication with others, socializing and many different daily activities that take place in the intimacy of the home. A key element of non-formal care is the affective quality of the relationship between receiver and provider of care. The term ‘family caregiver’ has been used in a similar way by other authors, defined

as ‘people who provide care to family members, life partners or friends whose sick, elderly or disabled, without paid and ‘is responsible for the physical, emotional, and financial supports of the family member who is unable to care for him/herself due to illness, injury or disability’ (Annisa, 2016). In this study, the terms informal carer, caregiver and figure of support will be used in a similar way.

Several authors (Brugha, 1995; Letourneau et al., 2007; Sherbourne & Stewart, 1991) have studied the dynamics and functions of social support in severe mental illness, having identified three fundamental aspects of it: 1) Type of support, which includes activities done by supporters, quantity of support and satisfaction with it; 2) Sources of support, like family, friends, organizations; and 3) Functions of support, which include affective and appraisal functions (like intimate relationships, expression of positive emotions and affections, empathic understanding and encouraging expression of feelings), informational functions (offering advice, information, guide, feedback), instrumental or tangible functions (provision of material aid or performance of specific activities and tasks), positive social interaction (which includes participation in recreational and enjoyable activities).

Informal care can relate and interact in different ways to formal care, being a substitute of formal care when the last is unavailable, being a complement to formal care with specific and different functions and tasks, or, in a more holistic perspective, interacting with the formal sector, generating ‘third ways’ of care (Colina, 2003).

Several authors like Colina (2003) consider that the interaction between the person in need, the social network and the health care institutions have to be properly understood in order to address and deal with any health problem. In the area of mental health, and in particular regarding support in parenting of women with severe mental illness, it is important to consider that the different paradigms of understanding mental illness and mental health care will influence the ways in which health care institutions understand and react towards the problematic, but also in the ways the woman and her social network understand and react towards it (Bhugra, 2006). There is some evidence linking societal narratives of mental illness with societal attitudes towards people suffering from a mental illness. For example, the study of Desviat et al. (1997) showed that social representations of mental illness and mental health care services have changed in regions that successfully underwent a psychiatric reform, with higher acceptance and normalization of mental illnesses and changes in ideas of dangerousness and confinement of the mentally ill. In the same line, the study of Saldivia et al. (2013b) about informal care in people with

schizophrenia, found a significantly lower degree of informal care for people with schizophrenia in Argentina compared to Spain and Brazil, which could be attributed to the predominance of care in hospitals and lower degrees of development of community care in Argentina.

1.3.3. Social support, parenting and parental competences

Several programs designed to support vulnerable families in care and raising of children, have tried to use preventive perspectives that focus on strengths and resources of parents within a context that will modulate their parental competences. Context, either supportive or stressful, is understood as having a powerful influence on parenting and on satisfaction of child needs. Context includes not only family but also the neighborhood and the socio-economic and cultural environment (Falkov & Lindsey, 2002; White, 2005). Influence of context can be so powerful that several groups devoted to the topic have considered that any intervention that has the aim of improving the quality of life of patients who are parents and of their children, must be based on the understanding of the situation of the parent and the child within the family, social and environmental context (Falkov & Lindsey, 2002). Not only the identification of available support results of importance in these situations, but also the identification of how well the support network works. This can be inferred by satisfaction of the receiver with the received aid, how much conflict arises from the supportive relationship, and the time and energy costs of supplying aid (Beeber & Canuso, 2005).

Parenting is considered as a series of 'tasks' that have the purpose of facilitating an adequate development of the child within a safe environment. These tasks include several dimensions, including parent's sensitivity to the child's needs, social communication, expression of emotions and control of discipline (White, 2005). In this perspective, a common concept used to assess and assist families is the concept of *parental competences*. These refer to the emotional, cognitive and behavioral resources of parents to be able to relate to their children and respond to their needs (Martín, Cabrera, León, & Rodrigo, 2013). A fundamental feature of parental competences is that they must be flexible, elastic and adaptable in order to adjust to the different types of needs children show according to their developmental stages, contexts and personal characteristics (Barudy & Dantagnan, 2010; Sallés & Ger, 2011). They will be molded by the psycho-social conditions of each family, the educational beliefs and practices used by the parents

and by the characteristics of the child, including his or her vulnerability and resilience (Rodrigo López, Martín Quintana, Cabrera Casimiro, & Máiquez Chaves ,2009).

Parental competences have been grouped under several categories, including capacity of attachment and empathic relationship with children, educative competences under a warm and affectionate relationship, parental agency, abilities to maintain adequate personal care and social relationships, abilities to organize the domestic environment and the ability to look for social support to complement the parental role without losing personal autonomy in this area (Rodrigo López et al., 2009; Sallés & Ger, 2011; White, 2005). As can be observed, the concept of parental competences refers to the function of parents that is related to take care, protect, educate and promote socialization of their children. It represents an integrative concept that not only focuses on the parents themselves but considers the role of social network and institutions to help and complement them in the care and raise of children (Sallés & Ger, 2011), and therefore allows a focus based on strengths within families (Rodrigo López et al., 2009).

1.3.4. Social support for mothers with severe mental iillness

As reviewed in the previous section, social networks of support can play a crucial role in parent, child and family outcomes when a parent has a SMI. Some parenting behaviors, including style of communication, warmth and praise, consistency, and the setting of limits, are usually learned and modeled from other family members (Seeman, 2013). Positive support can shape mothers' experiences, influence her role and attitudes and increase her parental competence, but can also moderate the impact of an unavailable parent on the child, acting as a buffer (Gelkopf & Jabotaro, 2012; Hearle & McGrath, 2000; Nicholson et al., 1998b; Reupert & Maybery, 2007).

Mothers with SMI, including schizophrenia, tend to recognize the need of a supportive environment and the need of assistance from their partners and close family members. They tend to have more supportive social networks than persons with SMI that do not care for a child, with support coming mainly from relatives (especially children's grandparents) and less likely from partners (Perera et al., 2014; Savvidou et al., 2003).

Support can take various forms, including involvement in daily parenting tasks, child assistance when the mother is unavailable, information and advice, emotional support, companionship (Nicholson et al., 1998b; Zemencuck et al., 1995), involvement in treatment and administration of medication, aid in material needs, and household duties

(Perera et al., 2014). Relatives, and sometimes friends, are frequently involved in the upbringing of the child (Hearle & McGrath (2000).

Although steady support has been associated to better outcomes in children (Gelkopf & Jabotaro, 2012), it is particularly needed during times of mental health crisis (Perera et al., 2014). During these periods children are frequently taken care by their father, family members or friends (Diaz-Caneja & Johnson, 2004; Joseph, Joshi, Lewin, & Abrams, 1999; Perera et al., 2014). When the mother feels validated in her role and when support emerges from relationships based on mutuality and reciprocity the influences of support on parenting have been described to be especially positive (Power et al., 2011).

Additionally, some authors have reported negative influences of the close network of many women with mental illness. Negative influences can stem from lack of understanding of mental illness, blaming, undermining or judgmental attitudes, indifference, anger, frustration, verbal and physical abuse, among others. Unrealistic expectations can make caregivers put a high pressure on the mother, while the adjudication of a 'sick' role leaves her out of the decision-making process, and makes supporters present intrusive or indulgent attitudes in her interaction with children (Nicholson et al., 1998b; Perera et al., 2014; Savvidou et al., 2003; Zemencuck et al., 1995). Partners and family members can also have a mental illness, can have problems of substance abuse or have history of dysfunctional parenting themselves. (Power et al., 2011).

1.3.5. Experiences of caregivers of people with severe mental illness

Studies performed in diverse western and non-western countries (Awad & Voruganti, 2008; Gutiérrez-Maldonado, Caqueo-Urízar & Kavanagh, et al., 2005; Lasebikan & Ayinde, 2013; Vermeulen et al., 2015) showed that the great majority of carers are women (around 80%), with a mean age of around 55 to 60 years in different studies. The great majority are family members, especially parents of the person with SMI (81.5% in the study of Lasebikan & Ayinde, 2013; 78.4% in Gutiérrez-Maldonado et al., 2005) and many live with the person they care for (50% in the study of Vermeulen et al., 2015). Second, with much less frequency, caregiver role is assumed by partners, with a percentage that varied from 1.5 % in the study in Chile of Gutiérrez-Maldonado et al. (2005), to 11.7% in the international study of Vermeulen et al. (2015). Additionally, some studies have found children taking on caregiving roles of their own mentally ill parents as well as of their siblings (Bee et al., 2014; Perera et al., 2014). Regarding employment, studies have shown variable results,

with the majority being retired (43%) in the study of Vermeulen et al. (2015), employed (60%) in the study of Lasebikan & Ayinde (2013) and unemployed (56.9%) in the study of Gutiérrez-Maldonado et al. (2005).

Family caregivers assume diverse tasks and responsibilities, playing a relevant role in regions were mental health policies have promoted the care of the severely mentally ill in their communities. Caring responsibilities are high, and carers usually are expected to be 'present, close by and available' for a task that tends to be long lasting in time (decades), time consuming and frequently assumed by one person which is the only or main carer (Chan, 2011; Vermeulen et al., 2015).

Caregivers frequently experience severe strains in their lives associated to their role, because very often they lack time for themselves, are not able to take a break from care, have to prioritize the needs of the person they care for before their own needs, cannot plan for their future, and restrict their personal, social and vocational aspirations (Awad & Voruganti, 2008; Chan, 2011; Vermeulen et al., 2015). Strains and amount of effort required to fulfill their roles affects the *quality of life* of caregivers and makes them experience several types of *burden* in different areas of their lives. Some authors have distinguished subjective and objective components of burden (Awad & Voruganti, 2008). Objective burden was described as the 'effects on the household including financial loss; effects on health, on children, and family routine; and the abnormal behaviors shown by the patient' (Lasebikan & Ayinde, 2013), while subjective burden referred to 'the extent to which relatives felt they carried a burden' (Lasebikan & Ayinde, 2013). This distinction has turned out to be unclear (Annisa, 2016) and other authors have preferred to classify burden according to the areas in which it appeared, describing emotional, social, physical, financial and relationship burdens (Vermeulen et al., 2015).

Emotional burden is in general related to the difficulties to cope with anxiety and anguish related to the caring role and tasks, and the appearance of negative feelings like sadness, depression, anger, resentment, guilt and exhaustion, as well as lack of sleep (Veltman, Cameron, & Stewart, 2002; Vermeulen et al., 2015). Caregivers frequently experience concerns and fears about safety of the ill person and themselves during relapses (Vermeulen et al., 2015) and have shown high rates of depressive disorders (Veltman et al., 2002; Vermeulen et al., 2015). *Social burden* is related to frequent experiences of social isolation, loneliness, distant relationships and lack of support from family and friends. (Caqueo-Urízar, 2014; Veltman et al., 2002; Vermeulen et al., 2015). Social

isolation can be provoked by lack of time due to caring responsibilities, but also by stigma associated to severe mental illness. Caregivers in several studies expressed to feel stigma falling on them, so that they felt blamed, misunderstood or not appreciated (Awad & Voruganti, 2008; Veltman et al., 2002; Vermeulen et al., 2015) and sometimes was perceived coming from health professionals (Veltman et al, 2002). Affection of own physical health in varying degrees due caring activities is related to *physical burden*, and has been mentioned by around 70% of caregivers in diverse studies (Awad & Voruganti, 2008; Vermeulen et al., 2015). *Financial burden* is related to worries about own financial situation and economic constraints (Awad & Voruganti, 2008; Vermeulen et al., 2015), but more frequently to worries about the economic situation of the person with SMI (Vermeulen et al., 2015). As well, caregivers are frequently worried about the person with SMI 'becoming too dependent on them in the future' (Vermeulen et al., 2015) which is associated to *relationship burden* (Gutiérrez-Maldonado et al, 2005; Vermeulen et al., 2015). Some studies have associated this burden to the lack of structures of support for patients regarding working and housing, so that these responsibilities fall on families (Veltman et al., 2002). In the same domain, it was frequent that caregivers talked about difficult interaction and relationship with the person they cared for, feeling strained, irritated or upset by them (Gutiérrez-Maldonado et al., 2005; Vermeulen et al., 2015).

Most caregivers experience burden in several life domains. Some studies have observed that the most frequent domains were caregivers express to feel strong burdens are in emotional wellbeing and in preoccupations about the future (Vermeulen et al., 2015). So, subjective burden would be higher than objective burden, which could be explained by stigma and lack of social support typically associated to schizophrenia and other SMI (Awad & Voruganti, 2008). Nevertheless, other studies showed similar degrees of subjective and objective burden (Lasebikan & Ayinde, 2013), financial burden being the most frequent or one of the most frequent expressed by caregivers in developing countries like Nigeria (Lasebikan & Ayinde, 2013) and Chile (Gutiérrez-Maldonado et al, 2005).

Some characteristic of carers have been associated to a higher expression of burden, including being a female caregiver, having a younger age, spending a large number of hours in caregiving, being the only caregiver and having short experience in caregiving (Annisa, 2016; Lasebikan & Ayinde, 2013; Vermeulen et al., 2015). Older age was associated to higher amount of physical and mental health affections (Gutiérrez-Maldonado et al, 2005; Lasebikan & Ayinde, 2013). Coping strategies could have an

impact on the experience of burden of caregivers, so that caregivers that use avoidance, collusion and coercion showed higher burden than the ones that use other strategies like resignation, avoidance, distraction, relying on faith and wishful thinking (emotion-focused or passive strategies), or problem-focused strategies (active strategies). Between these, active strategies were the ones related to less burden in caregivers (Annisa, 2016; Veltman et al., 2002, p.109). At the same time, having social support, possibilities to take a respite and reduce social isolation are factors that can decrease experienced burden (Gutiérrez-Maldonado et al, 2005). As well, caregivers of older age and with more experience in care, and the ones that have received family interventions experienced a decrease in the burden (Awad & Voruganti, 2008; Vermeulen et al., 2015).

Positive aspects of the supporting role were highlighted by several authors like Vermeulen et al. (2015), Awad and Voruganti (2008) and Veltman et al. (2002). These included an increase in the understanding for people with problems, reducing judgmental attitudes, increasing patience, experiencing positive feelings of love and compassion, increasing inner strength and resilience and improving the relationship with family members. Some caregivers consider their function as 'a voluntary and self-satisfying act' with negative aspects but not burdensome, but in general positive aspects associated to the role of caregiver do not seem to be enough to counteract the negative aspects. Vermeulen et al. (2015) described 30% of the caregivers they interviewed to consider themselves to be in a 'breaking point'

It seems to be difficult to find a balance between the responsibilities associated to the role of careres and the preservation of own health and quality of life (Vermeulen et al., 2015). The great majority of carers in several studies considered that they needed additional support in their role as carers, and in second place the great majority talked about the need of having respites from care, which was not always possible (Veltman et al., 2002; Vermeulen et al., 2015). Many supporters thought that health care services should assist them in those needs (Veltman et al., 2002).

Regarding their *relationship with formal professional mental health care*, satisfaction varied among users. Most were dissatisfied about information regarding evolution of illness in the long term, information on whom to contact in cases of emergency, involvement in decisions regarding care, communication with medical staff, and non-supportive attitudes of professionals (Vermeulen et al., 2015). Caregivers were eager to talk about their experiences, burdens, and suggestions they would have for the health care system, and

felt they were being neglected in their needs, unrecognized and left without support (Veltman et al., 2002). Nevertheless, the most important need the majority expressed was having additional support (Vermeulen et al., 2015). Worth noticing is that family caregivers tended to be more satisfied with the support given by family or patient organizations than the one coming from professional sources of care (Vermeulen et al., 2015).

This implies that family caregivers are not adequately recognized and integrated in mental health care, neglecting the needs of additional support that families require when care responsibilities are transferred to them (Vermeulen et al., 2015).

1.4. CONCLUSIONS OF THE LITERATURE REVIEW

Social and community support, as part of social determinants of health, exert a great influence on general health and mental health. Among them, poverty and social exclusion, gender, and the consequences of violence are considered as main risk factors for mental disorders. These are common conditions among mothers with SMI, and the vicious cycle of poverty and mental illness can affect not only them but their children as well.

Following the tendencies to approach health problems with preventive strategies and with interventions that address social determinants, social support has been promoted as an important aspect of mental health care. To reduce the burden of mental disorders, support of families and social cohesion are currently considered as areas where public health interventions need to be promoted and developed. As well, social support has been considered as a recourse of care and aid for parents in vulnerable conditions, including mothers with SMI. A change of perspectives has occurred in this area, with a shift from deficit and risk-oriented understandings to resource-oriented perspectives that include contextual aspects as protective for mother and child and to be considered as resources of care.

Because of several contextual disadvantages, which include poverty, low educational background, social isolation, lack of support and difficult relationship with their families, women with SMI that have children are considered as some of the most vulnerable groups in society. Worryingly, children of parents with SMI tend to experience diverse negative consequences, including cognitive, behavioral and developmental problems. They are at higher risk of poorer general health and higher risk of psychological and psychiatric disorders in the lifespan, when compared to children of parents without SMI.

Contextual disadvantages add to difficulties in parenting caused symptoms of illness and adverse effects of medicines. But strengths in parenting and positive aspects of maternity have extensively been identified among these mothers as well, opening the possibility to focus on strengths and try to improve their deficits mobilizing social and community resources of support. Nevertheless, social support is still scarce and appears to be problematic in several areas. Negative influences of their context have been described on people with SMI, and negative aspects of caregiving have been identified among figures of support. These aspects suggest the need to improve the understanding of the process of care in these situations, identify problematic areas and unsatisfied needs of support.

CHAPTER 2:
PURPOSE OF THE STUDY AND RESEARCH QUESTIONS

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2.1. OBJECTIVES OF THE STUDY

The ***main objective*** of the study was to explore the experiences and needs of support in parenting in daily life of women with schizophrenia and related disorders, according to the mothers and their main caregiver, comparing two contexts with different organization of mental health care (Mendoza, Argentina; and Granada, Spain).

The ***secondary objectives*** are:

- To characterize and compare the groups of mothers and caregivers in both countries, regarding socio-demographic characteristics. Mothers will be additionally characterized regarding clinical aspects, which include diagnosis, illness onset and place of treatment.
- To describe and compare the organization of mental health care services in both sites of study.
- To explore strengths and difficulties in parenting of women with schizophrenia and related disorders, as expressed by mothers and their caregivers in both sites of study
- To explore the sources of social support of mothers with schizophrenia and related disorders, as well as their functions, activities and strategies regarding support in parenting, from the perspectives of mothers and their main caregivers in both sites of study.
- To explore the problems that appear in the process of giving and receiving support in parenting, from the perspectives of mothers and their main caregivers in both sites of study.
- To detect unfulfilled needs of support in parenting as expressed by mothers and their main caregivers in both sites of study.

- To explore the experiences of support in parenting received from formal sources of mental health care and other institutions participants considered relevant, from the perspectives of mothers and their main caregivers in both sites of study.
- To explore the influence that experiences with formal sources of care exert on the experiences with informal care, as expressed by mothers and their caregivers in both countries.
- To compare the similarities and differences between the accounts of mothers and supporters, and between these groups in both countries, regarding their experiences and unfulfilled needs of support in parenting.

2.2. RESEARCH QUESTIONS

*The **main research question** was:*

Which are the experiences and needs of support in parenting in daily life expressed by women with schizophrenia and their main caregivers, in two contexts with different organization of mental health care, namely Spain and Argentina?

***Secondary questions** were:*

a. Socio-demographic characteristics and clinical aspects:

- What are the socio-demographic characteristics of mothers and their caregivers regarding age, educational level, working status, economic status and civil status? What are the differences and similarities among both countries regarding these aspects?
- What is the psychiatric diagnosis, period of onset and place of treatment of mothers that participate in the study? What are the differences or similarities among both countries regarding these aspects?

b. Experiences of maternity:

- What are the difficulties and strengths in parenting of mothers with schizophrenia and related disorders, as expressed by mothers and caregivers in both sites of study?
- How does mental illness affect parenting, as expressed by mothers and their caregivers in both sites of study?

- Are there similarities and differences in the accounts of mothers and supporters, and between both sites of study, regarding these questions?

c. *Experiences of support in parenting in daily lives:*

- Who provides support in parenting in daily lives for mothers with schizophrenia and related disorders?
- What activities do caregivers perform to support mothers in their parenting? How do they manage to organize and provide this support?
- What problems appear during the process of giving and receiving support in parenting?
- How do experiences with formal care influence the way participants organize, provide or manage support in parenting in daily lives?
- Are there similarities and differences in the accounts of mothers and supporters, and between both sites of study, regarding these questions?

d. *Experiences of support from formal care regarding the mothering role:*

- How are mental health care services organized in both sites of study?
- How do women with schizophrenia experience support for their mothering role from mental health care services and other institutions considered relevant by participants themselves?
- Are there similarities and differences in the accounts of mothers and supporters, and between both sites of study, regarding these questions?

e. *Unfulfilled needs of support in parenting*

- Which needs of support in parenting in daily lives do mothers and caregivers consider to be unfulfilled by the support they were receiving?
- Which needs of support in parenting coming from formal sources of care do mothers and caregivers consider to be unfulfilled by the support they were receiving?
- Are there similarities and differences in the accounts of mothers and supporters, and between both sites of study, regarding these questions?

CHAPTER 3:
METHODOLOGY AND METHODS

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3.1. TYPE OF STUDY

The research was conceived as a qualitative exploratory and interpretative study with a comparative design. A quantitative descriptive component was added to describe the characteristics of the studied population and the recount of themes within the qualitative part.

The research intends to approach the phenomenon of study in its complexity, from a holistic perspective, trying to grasp the meanings associated to mental illness, caring roles and family relationships and the influences of the context in the development of those experiences and meanings. These aims are in accordance to the basic principles of descriptive and interpretative qualitative research (Rosenberg, 2012; Vázquez Navarrete et al., 2006). Qualitative approaches aim to reach an in-depth understanding of studied phenomena, from the perspective of the ones that experience it. They consider reality to be multiple and put special attention to commit to the participants' points of view as well as respecting their natural context as much as possible (Vaismoradi, Turunen, & Bondas, 2013; Vázquez Navarrete et al., 2006).

Within qualitative methodologies, qualitative content analysis was chosen as the approach to analyze and interpret data in this study. Qualitative content analysis can be defined as 'a research method for making replicable and valid inferences from data to their context, with the purpose of providing knowledge, new insights, a representation of facts and a practical guide to action' (Elo & Kyngäs, 2008, p. 108). It has the aim of describing the phenomenon in a condensed and broad way, and the final product of analysis is the creation of categories that describe it (Elo & Kyngäs, 2008). Other authors have stressed the systematized character of the method, defining it as 'an approach of empirical, methodological controlled analysis of texts within their context of communication, following content analytical rules and step by step models, without rash quantification'. (Mayring & Fenzl, 2014, p. 546). Quantification is not always performed, but only if required by the research question (Mayring & Fenzl, 2014). Qualitative content analysis has expanded the

use of content analysis to deal not only with manifest but also latent content of communication (Graneheim & Lundman, 2004). The manifest content refers to what is said in a text in a visible way, while the latent deals with the underlying meanings of what is being said. The identification of both, manifest and latent content, deals with interpretation but with different depths and levels of abstraction (Graneheim & Lundman, 2004). Some authors differentiate levels of content, identifying themes and main ideas of a text as manifest, and context information as latent content (Mayring & Fenzl, 2014). In this study, special consideration was given to the influence of formal health care into the dynamics of informal care, with the hypothesis that the understandings of mental illness, roles of the mentally ill and roles of caregivers that circulate in formal settings will have a strong influence on the ways in which informal care is organized and understood.

Finally, it is important to consider that qualitative methodologies gain in deepness but cannot provide statistically generalizable information. Still, they can provide analytic generalizations and transferability to similar contexts (Miles & Huberman, 1994; Polit & Beck, 2010). In qualitative studies, researchers identify information that is relevant to all or many participants, distinguishing it from the information that is relevant to unique participants. In this way, it is possible to identify and conceptualize processes. While interpreting data, and creating concepts on the described processes, inductive generalizations are made, which authors like Polit and Beck (2010) describe as *analytic generalizations*. This type of analysis allow data to be extrapolated to similar contexts than the ones in which research was performed, so that similar experiences are expected to appear in similar settings and contexts, a characteristic usually referred to as *transferability to similar contexts* (Polit & Beck, 2010).

3.2. STUDIED POPULATION

The study was performed in two regions of different countries, namely Granada in Spain and Mendoza in Argentina. These regions were chosen because of their similar characteristics regarding geography, size, number of population, language and cultural characteristics and its difference in the organization of mental health care.

The province of Granada, located in the autonomous community of Andalucía, has a population of 922.138 inhabitants in 2013. Approximately 530.000 living in the metropolitan area (INE, 2014), constituted by 32 municipalities (Aguilera Benavente, 2010). The province of Mendoza counted with 1.738.929 inhabitants in 2010, of which 788787 live in

the metropolitan area (Argentina, Ministerio de Hacienda y Finanzas Públicas. INDEC, 2010), constituted by six municipalities: Capital, Godoy Cruz, Guaymallén, Maipú, Luján and Las Heras (Marina-Berón, Padila-Rodriguez, & Rapalí, 2013). Both regions are located in mountainous areas and devote their main economic activities to agroindustry, and secondarily to industry and services (Aguilera Benavente, 2010; de Oña López, 2004; Usach, 2005). Both countries, Spain and Argentina, have a close connection through past immigration. This was especially important in the period of 1870-1930 when Argentina received massive immigration form diverse south European countries, which was crucial for the constitution of the Argentinian society, including social, political, economic and cultural aspects (Esteban, 2003).

An important difference among both countries resides in the organization and provision of mental health care. In Argentina, mental health care is mainly based in hospital psychiatry, with less development of community and rehabilitation services (Saldivia, 2013). Currently Argentina is transiting a process of psychiatric reform on the national level since the year 2010, when the National Law on Mental Health was enacted (Ley Nacional de Salud Mental N° 26657). Previously some pioneer initiatives of deinstitutionalization were performed but most of them were small and transient (López-Santi, 2011). The province of Mendoza continues with a traditional organization of mental health care, concentrating much of mental health care for the severe mentally ill in two psychiatric hospitals of the metropolitan area. Mental health care is also being provided in primary health care centers of the whole province, but until now these services have failed to capture the demand of the severe mentally ill. On the contrary, Spain started its psychiatric reform in 1985 (Lafuente Lázaro, Francisco González, Criado Martín, & Covarrubias Fernández, 2007) with the aim of integrating mental health care with primary health care, adopting a public health focus and giving a central role to communities and interdisciplinary teams (Desviat, 2010). The reform was not a homogeneous process along the whole country, but reached different magnitudes according to the local policies of each autonomous community. One of the communities that achieved a reform of greater magnitude was Andalucía, which is the reason why it was chosen as the site for field work (López, Benítez, García, Weissman, 1998). The mental health care services in Granada, as in the rest of Andalucía, consist in a network of services with territorial organization integrated to the national general health care system, and a network of social services that are independent from the health care system and are organized by FAISEM, the Andalusian foundation for social integration of the mentally ill (López, 2004). The basic units of specialized mental health

care are the community mental health units (*Unidades de Salud Mental Comunitaria*), integrated in the community and frequently located in primary health care facilities. These provide integral mental health care to patients in their homes or ambulatory facilities and coordinate care with the rest of units. Units for brief hospitalization are integrated in general hospitals, and state psychiatric hospitals were progressively and completely closed along seventeen years of reform (Torres-Gonzalez, 2012a; Valmisa Gómez de Lara et al., 2008). Other various resources for mental health care were developed, among which one of the most relevant ones are social mental health services integrated foundation for the social integration of the mentally ill (*FAISEM- Fundación Andaluza para la Integración Social del Enfermo Mental*).

3.3. SUBJECTS OF THE STUDY

Subjects of the study were women with schizophrenia that were mothers of children under 18 years of age and resided in the community, and the main figure of informal care of these mothers that provides support in the mothering role in daily life. Participants were selected according to the inclusion and exclusion criteria listed in Table 3.

Table 3
Inclusion and exclusions criteria

Mothers	*Inclusion criteria:* • Diagnosis of schizophrenia and related psychosis according to the International Classification of Diseases 10th version (F20-29, ICD 10) confirmed by OPCRIT+ (McGuffin, Farmer, & Harvey, 1991; Rucker et al., 2011) • Living in the community • Attending out-patient mental health care services • Being mother of children under 18 years of age, and caring for at least one of their children • Giving written informed consent to participate in the study
	Exclusion criteria • Age of the mother under 18 years • Age of the youngest child over 18 years • Moderate or profound intellectual disability • High degrees of institutionalization [defined as more than 15 years of contact with the formal mental health care system, history of psychiatric hospitalization for more than 40% of the preceding 3 years and more than 3 months in the preceding year (Saldivia et al., 2013a)] • Presence of acute psychotic symptoms during the moment of interviewing

	• Lack of autonomy in basic personal and social performance indicated by a score 1-10 (out of 100) in the Personal and Social Performance Scale (Apiquian et al., 2009) • Negative to give written informed consent to participate in the study
Informal carers	*Inclusion criteria:* • Being the main provider of non-professional care and support in daily lives, acknowledged as such by the mother and by herself/himself • Living with or having a close emotional connection with the mother with schizophrenia • Giving written informed consent to participate in the study
	Exclusion criteria: • Being part of mental health services or other formal services • Negative to give written informed consent to participate in the study

3.4. PROCEDURES OF RECRUITMENT

Participants were recruited through mental health care institutions of the metropolitan areas of Granada (Spain) and Mendoza (Argentina). The metropolitan region of Granada counts with four community mental health care centers, located in the municipalities of Zaidín, Cartuja, Atarfe and Santa Fe, and with one unit of child and adolescent mental health care, located in the city of Granada. Professionals of all these units were contacted to recruit participants. In the metropolitan region of Mendoza, Argentina, ambulatory mental health care is provided in two psychiatric hospitals (Hospital El Sauce and Hospital Dr. Carlos Pereyra), in primary health care centers located in each department (Capital, Godoy Cruz, Las Heras, Guaymallén, Luján, Maipú) and in child and adolescent mental health units, located in the same departments. To recruit participants, ambulatory services of both hospitals were contacted, as well as the mental health care teams of primary health care centers and one child and adolescent mental healthcare center.

Several mental health care professionals of these institutions were contacted through the coordinators or directors of mental health care of each region. Objectives of the research and inclusion/exclusion criteria were explained to these professionals so that they revised the files and records of their patients to identify potential participants. During a consultation or by a phone call, professionals briefly explained the potential participants about the project and asked them if they would accept to be contacted by phone by the researcher to receive more information about the study and be invited to participate. Voluntary character of participation, confidentiality of information, and independence of their health care was

stressed. Participants that agreed to be contacted were called by phone by the researcher. In this first contact the researcher introduced herself with her name, professional background, nationality, and explained the objectives of the research and what participation in the research would consist of. Again, the voluntary character of participation, confidentiality of information and independence of their health care was stressed, as well as the possibility of asking more questions and decide about their participation in a face to face meeting. Finally, the potential participants were invited to participate in the study in company of the person identified by themselves as the main figure of support in their mothering tasks in daily life. Date and place of the interview were jointly decided with participants. Places that allowed to have a private dialogue, with little noise and no interruptions were chosen. In Granada three places were offered: an office at the University of Granada, an office in the health care center where they received mental health attention, and participant's homes. In Mendoza two places were offered: the mental health care centers where the participants received attention and participant's homes. Finally, in both regions the possibility of holding a telephonic interview was offered if it was not possible to combine a personal encounter.

3.5. DATA COLLECTION PROCEDURES

3.5.1. Semi structured interviews

The objects of analysis chosen for this study were interviews. Interviews within qualitative studies are understood as an effective method to gain insight into participants' feelings, ideas and experiences, and into the ways in which they interpret and assign meaning to them (Mack, Woodsong, MacQueen, Guest, & Nameyet et al., 2005; Merlinsky, 2006; Vázquez Navarrete et al., 2006). The personal information obtained is not understood as pure or simple facts, but as facts that the person gives meaning to, so that facts will always be interpreted facts. Meaning is understood as being constructed and influenced by wider social meanings, personal understandings and understandings created in the interaction with the interviewer (Merlinsky, 2006).

The number of interviews was preliminary defined considering the research objectives, characteristics of the studied population- size, diversity, availability, as recommended by authors like Mack et al. (2005). Additionally, previous evidence about the number of interviews necessary to reach saturation in qualitative studies was considered, as has been studied by Guest, Bunce and Johnson (2006). These authors showed that saturation

tends to occur within the first twelve interviews, while some more basic elements were already present at the number of six interviews. The final number of participants was determined based on the criteria of theoretical saturation, following the recommendation of several authors devoted to the issue of sampling in qualitative research (Mack et al., 2005; Miles & Huberman, 1994; Silverman & Marvasti, 2008; Vázquez Navarrete et al., 2006). These authors consider that theoretical saturation is reached when new data are repeated, redundant or do not bring new insights into the research questions

a. Construction of interview guides

To lead the interview in a semi-structured way, two guides were developed: one for interviewing mothers and one for interviewing caregivers. Both guides have similar content, but differ in some aspects that will be explained in the following lines.

Content of interview guides was developed based on research aims and research questions. Five main topics were addressed in the guides for mothers, namely: a) experiences of motherhood, b) perceived needs of support in mothering tasks in daily life, c) description of received support in mothering tasks in daily life, d) experiences of support in mothering tasks in daily life, and e) satisfaction with received support. In case of caregivers, the main topics addressed were: a) perceived needs of support in daily life in mothering tasks of the mother with SMI, b) description of given support in mothering tasks in daily life, c) experiences as a supporter, d) impact on own life and own needs of support as main figure of support in daily life of the mother with SMI.

These topics were included in a set of predetermined open-ended questions to elicit reflections and narratives of the interviewees. More specific questions and follow up questions were developed to complete information and to go deeper into different aspects of the mentioned topics, following the advice of DiCicco-Bloom and Crabtree (2006). Questions were constructed to be used in a flexible and adaptable manner, while making sure that the same general topics would be addressed during the interview, in accordance with the general interview guide approach mentioned by McNamara (2009) and Turner (2010). Flexibility and adaptability of use refers to the possibility of questions to be rephrased during the interview in accordance with the vocabulary and communicational style of the interviewee, and to the possibility of admitting the emergence of additional follow up and probing questions during the interview process (DiCicco-Bloom & Crabtree, 2006; Fiese & Spagnola, 2005; Mack et al., 2005).

Language was kept simple and concrete so that questions could be easily understood. These aspects were considered extremely important since people with schizophrenia and related disorders characteristically present cognitive difficulties that can impair their abilities to attend and comprehend (Brissos, Molodynski, Dias, & Figueira, 2011).

After their first development, both guides were tested in simulated interviews with colleagues, to probe if questions were clear, understandable and appropriate to the intended purpose. Afterwards they were tested in one pilot interviews with participants. Through these probes some questions were re-phrased and some taken away, because they did not elicit the necessary information or because they elicited redundant information, following the recommendations of DiCicco-Bloom and Crabtree (2006).

After the first interviews to participants, again some questions were re-phrased and two new topics that spontaneously emerged during the conversation were included in the guide. These items were: 1) Support given by formal institutions like educational institutions, which was added as sub-question in the description of received support; 2) Own needs of support of informal carers, added as second part of the question that explores impact of care on life of informal carers.

b. Conduction of interviews

Interviews were conducted during the months of March-July of the year 2014 in Spain, and during the months of August-October of the same year in Argentina. Time and place of the meeting were previously arranged with participants by phone. Interviews were conducted in the health care facilities through which participants were recruited, and in homes when people could not mobilize to the proposed place. Some interviews were held on telephone because people could not assist and lived in areas the researcher could not reach because of safety or excessive distance.

During the first contact with participants the researcher introduced herself with her name, professional background, status as a doctoral student and country of origin. The nature, objectives and methods of the research were thoroughly explained, as well as the ways results would be presented. Voluntary character of participation, confidentiality, anonymity and independence of the research with health care were stressed. It was strongly clarified that the interview was not an instance of surveillance or judgment, and that the given information would by no means affect the health care of the mother, child or family. Potential participants were encouraged to ask questions about the study. They were given

different ways to contact the researcher and the ethical boards of the institutions through which they were contacted, in case they would like to obtain additional information on the research or would like to clarify aspects of the given information after the interview was conducted. If the potential participant agreed to participate, written informed consent was obtained. Finally, it was asked if interviews could be audio-recorded, and if accepted this was included in the written informed consent.

After informed consent was obtained the interview started, putting special attention on the rapid development of rapport following the advice of DiCicco-Bloom and Crabtree (2006). With this purpose, interviews started with broad and non-threatening questions, referred to family composition and history of the mental illness and treatment. This information was considered not only necessary as background but also allowed a gradual approach to the main research topics. Since maternity and mental illness is usually a sensitive topic, it was especially considered that questions were posed in a non-threatening way and more sensitive information was only approached after it spontaneously emerged from the interviewee.

Interviews were conducted individually and one single-time with each participant, with a programmed duration of 30- 90 minutes. They were recorded in digital records and backup notes were taken, documenting contextual aspects, attitudes and behavior of the participants, following the advice of Mack et al. (2005). In the last minutes of the encounter additional information was gathered by de administration of questionnaires regarding socio-demographic characteristics of mothers and caregivers. Mothers with mental illness were additionally applied questionnaires for diagnostic validity and for assessment of social and functional performance.

3.5.2. Choice and application of questionnaires and scales

In addition to the interviews some brief questionnaires were used to obtain relevant information about socio-demographic characteristics of all the participants and to confirm diagnosis and assess personal and social performance of the participants with severe mental illness.

a. Socio-demographic questionnaire

To collect information about socio-demographic characteristics a questionnaire was constructed including information about gender, age and date of birth, nationality, civil

status, number of children and their ages, group of cohabitation, current occupation, last occupation in case of unemployment, educational level, place and type of housing, satisfaction with economic level, satisfaction of basic needs, monthly average income in the home.

b. Questionnaire for diagnostic confirmation: OPCRIT +

The recruitment of participants with schizophrenia and related disorders first relied on the diagnosis made by the mental health care professionals that identified the patient and facilitated the contact with her. When the patient admitted participating in the study diagnosis was confirmed through OPCRIT+. OPCRIT+ is an electronic system for psychiatric diagnosis in research and clinical settings, designed by Rucker et al. (2011) based on the expansion of the original OPCRIT system developed by McGuffin et al. (1991). The original OPCRIT tool was designed to diagnose psychotic illness (McGuffin et al., 1991), but later versions incorporated a broader range of diagnostic categories including substance misuse, anxiety, personality, eating disorder and dementia (OPCRIT, 2014).

The tool consists in a checklist of signs and symptoms related to psychopathological aspects usually observed during a standard psychiatric history and mental health state examination. The tool provides a definition of these items that are scored in electronic or paper format following a standard clinical assessment, a structured interview, case notes or abstract, or a combination of sources. The tool then applies an algorithm for diagnosis based on diagnostic classifications as ICD-10 and DSM-IV (Rucker et al., 2011).

The tool has shown good inter-rater reliability scores (combined weighted kappa for diagnostic reliability among all groups of diagnoses was 0.7, and for psychotic disorders 0.63) (Rucker et al., 2011). Good inter-rater reliability has been shown with raters from different geographical and theoretical backgrounds, with the original OPCRIT system (Williams, Farmer, Ackenheil, Kaufmann, & McGuffin, 1996).

Additionally, the original OPCRIT diagnostic system showed good to excellent agreement with diagnosis made by trained clinicians according to consensus, best-estimate, lifetime procedures, for diagnosis of schizophrenia and bipolar disorder (Craddock et al., 1996). OPCRIT showed superiority over other diagnostic tools because it includes a wide range of psychotic symptoms and includes lifetime-ever occurring symptoms (Cardno et al., 1999).

Other important advantages mentioned by Williams et al. (1996) are its flexibility, practicability and the use of a combination of operational definitions with a 'bottom-up' potential given by the multiplicity of signs and symptoms that are considered to reach diagnosis.

Limitations of this diagnostic tool include the influence of multiple factors that can affect scoring, including time constraints, experience with psychopathology and psychiatric diagnosis, knowledge about the specific case that is being rated, and experience with OPCRIT (Rucker et al., 2011). Since the tools intends to provide objective criteria for psychiatric diagnosis, it inherits the controversy about the use of objective criteria for diagnosis in mental health (Rucker et al., 2011).

This tool was chosen for confirmation of diagnosis because of its good psychometric properties, the multiple sources of information that are accepted to assess signs and symptoms, the inclusion of live-ever occurring events and the alignment of the obtained diagnosis with ICD-10 diagnostic criteria. ICD-10 is the classification of diseases used in both countries where the study was performed.

c. *Scale to evaluate personal and social functioning: Personal and Social Performance Scale (PSP)*

Personal and social functioning was assessed because of its possibility of affecting parenting abilities, so that participants with very low scores (10 or lower) would be excluded from the research. Social functioning has been defined in several ways, usually related to other close concepts like social outcomes, social integration and inclusion, social adaptation, standard of living, needs for care and quality of life (Priebe, 2007). A useful definition of social functioning is the one of Figueira and Brissos (2011, p.2) that considers it as "the capacity of a person to function in different societal roles such as homemaker, worker, student, spouse, family member, or friend. The definition also takes account of an individual's satisfaction with their ability to meet these roles, their ability to take care of themselves, and the extent of their leisure and recreational activities".

Social functioning is frequently affected by SMI, especially schizophrenia, where functional deficits are considered a core feature of the disorder and an indicator of outcome. They can appear in early stages, during acute phases or as part of residual symptoms and include poor social interaction, difficult inter-personal relationships and inadequate performance at studies or work (Brissos et al., 2011). Improvement of psychosocial functioning and quality of life is considered an important goal of treatment for people with SMI, but achieved less frequently than symptomatic remission. Consequently, measures of

social functioning are of importance when need and success of treatment is assessed. But these measures have been controversial due to variation in definitions of social functioning, variation in scoring depending on the source of information, influence of cultural understandings of acceptable recovery, and influence of contextual factors on outcomes (Brissos et al., 2011; Figueira & Brissos, 2011; García- Portilla et al., 2011; Priebe, 2007). Several scales have been developed to measure social functioning but they tend to be detailed, time-consuming, require deep knowledge of the patient's situation and require staff straining, or include symptoms that can influence the scoring of social functioning (Brissos et al., 2011; Figueira & Brissos, 2011; Priebe, 2007). To overcome most of these limitations, Morosini, Magliano, Brambilla, Ugolini, and Pioli (2000) have designed the Personal and Social Performance Scale (PSP) that measures psychosocial functioning in patients with SMI. This scale is based on the social functioning component (Social and Occupational Functioning Assessment Scale- SOFAS) of the fourth version of the Diagnostic and Statistical Manual of Mental Disorders. It is designed as a rating scale with 100 items that refer to the patient's functioning in four main areas: self-care; habitual social activities, including studies and work; social and personal relationships; aggressive and disturbing behaviors. Information is obtained through a semi-structured interview and the degree of disability in each area is assessed according to operational criteria defined by the authors and rated on a six point Likert scale. Additional information to the one obtained through the interview is considered to produce the final rating (Brissos et al., 2011; García- Portilla et al., 2011; Morosini et al., 2000). Advantages of the scale include its independence form clinical symptoms, the inclusion of several dimensions of functioning, its solid psychometric properties (alfa 0,874 for internal consistency and 0,979 for test-retest reliability in the study of García-Portilla et al., 2011- considering that 0,7 is the lower limit to indicate adequate reliability), excellent inter-rater reliability, its sensitivity to changes over time, its facility and brief time of application and no need of training for application (Brissos et al., 2011; García-Portilla et al., 2011; Morosini et al., 2000). In addition, it has been validated in several countries, in both acute and stabilized patients (Brissos et al., 2011; García-Portilla et al., 2011). Given its facility of application, use of different sources to produce the final rating and good psychometric properties, the PSP was chosen as scale to assess personal and social performance.

3.6. ANALYSIS OF DATA

Information obtained from socio-demographic questionnaires and questionnaires OPCRIT+ and PSP was analyzed through descriptive statistics (frequencies, mean, standard deviation).

Data from interviews were recorded and transcribed verbatim, following recommendations of Davidson (2009). Content was analyzed with the assistance of the software AtlasTi (Friese, 2012). The method of analysis was qualitative content analysis, which puts the focus on the manifest content of narratives and its interpretation but also allows the researcher to reach a more profound level of analysis where the manifest content can be articulated with factors that determine it, as psychosocial and cultural context (de Souza Minayo, 2010; Vázquez Navarrete et al., 2006). Within this technique, analysis is centered around the creation of *categories*, which are defined as 'a group of contents that shares commonality' (Graneheim & Lundman, 2004, p. 107). Through the creation of categories, the text is reduced into its more significant expressions, so that they constitute the expressions and ideas around which content is organized (de Souza Minayo, 2009). Another important concept for analysis is the concept of *theme*, described as a pattern or regularity of response, ideas and meanings within data, that captures something important in relation to the research question, and integrates disparate pieces of data in a coherent way (Braun & Clarke, 2006; Clarke & Braun, 2013; Graneheim & Lundman, 2004; Vaismoradi et al., 2013). Themes can be identified within or across categories (Graneheim & Lundman, 2004).

The following steps for qualitative content analysis have been followed, as suggested by Vázquez Navarrete et al. (2006) and Miles and Huberman (1994):

1. *Reading and organizing data (descriptive and classificatory phase)*: in this phase, different contents of texts were identified as well as their position in the text. Second, data in the texts were segmented according to participants' characteristics (type of informant- mother or informal carer- and region of study). Then, data were segmented according to themes represented in phrases or paragraphs in the texts.
2. *Creation of categories and subcategories (first analytic phase)*: categories are created according to the themes and contents that appear in the data, like opinions, values, intentions, actors, places, etc. In this study, categories were created in a combined deductive and inductive way, starting with a set of pre-

determined categories elaborated from interview guides and previous theories, and later adding new categories that emerged inductively.

Later, information related to each category was grouped, compared, and sub-categories were created. Sub-categories refer to different aspects of information included in each category.

3. *Synthetizing data:* information related to each category was summarized, including examples in the form of textual citations that show information of common or exceptional aspects.
4. *Description of results*: summarized information was described looking for similarities, differences and contradictions.
5. *Interpretation*: associations and explanations that give sense to the data were developed.

It is important to remind that the process of analysis is iterative, meaning that it is a cyclic process which involves several back and forth movements from data to analysis (Vázquez Navarrete et al., 2006).

Quality of research was controlled following criteria of theoretical and methodological adequacy, credibility, transferability, consistency, reflexivity and relevance according to mechanisms described by Vázquez Navarrete et al. (2006). These include revision of adequacy of the problem, method and design; selection of a pertinent and sufficient sample of participants; systematic and careful collection of data during field work and analysis of data; revision of results with participants after the interview; control by an external analyst and triangulation of sources of information (contrasting view from mothers and main informal carers).

3.7. ETHICAL ASPECTS

Ethical approval from the research ethical committees of the participating institutions was asked in advance. Informed consent was obtained in accordance to each country's guides and norms. Confidentiality and anonymity of information was guaranteed to participants, as well as independency of participation in the study from the care they and their children receive. Formal aspects of these ethical principles were considered, following the criteria imparted by law 41/2002 in Spain (Ley 41/2002, 2002), which regulates patient's autonomy, rights and obligations regarding information and clinical documentation and law 15/1999 of protection of personal data (Ley 15/1999, 1999). In Argentina, law 26529 (Ley

26529, 2009) and law 25326 (Ley 25326, 2000) regulate the rights of confidentiality and protection of personal data.

CHAPTER 4:
RESULTS

CHAPTER 4
RESULTS

4.1. GENERAL INTERVIEW DATA, SOCIO-DEMOGRAPHIC AND CLINICAL CHARACTERISTICS

4.1.1. GENERAL INTERVIEW DATA

A total of fifty interviews were performed, 28 to mothers with schizophrenia and related disorders (16 in Mendoza and 12 in Granada), and 22 to their caregivers (12 in Mendoza and 10 in Granada). Results regarding general interview data will be exposed per region.

a. Region of Mendoza, Argentina

In Mendoza, a total of sixteen mothers with schizophrenia and related disorders were interviewed. As shown in Table 4, this group of participants was recruited mainly through professionals of ambulatory services of one of the main psychiatric hospitals of the metropolitan region of Mendoza (Hospital El Sauce). These professionals mainly included psychiatrist, but also social workers. Mental health care teams form primary health care centers were contacted to recruit participants, but no patient was identified that could participate in the study. These teams explained that they did not count with people with psychosis among the population they cared for. Most encounters with mothers were held in the ambulatory facilities of el Sauce Hospital, followed by participant's homes.

The group of mothers with SMI in Mendoza showed various figures of support in mothering tasks in daily life. The most frequent was their own mother (25%), followed by husband or cohabitant partner (18.75%). One mother did not identify any figure that provided her support or help in mothering tasks in daily life.

It was possible to recruit twelve of these figures of support for the study. Recruitment was done through the mother with SMI who facilitated their contacts and first approved their participation in the study. Three main figures of support could not participate, two because of lack of time and one because the mother with SMI did not approve participation in the study. As shown in table 4, interviews were held mainly at the ambulatory facilities from El

Sauce Hospital, or at the participant's home. Worth noticing is that several interviews with caregivers had to be reprogrammed several times because of their busy schedules, and one had to be held by telephone because of the same reason.

Table 4

General interview data. Mothers and supporters, Mendoza (%)

	Mothers (n=16)	Informal Carers (n=12)
Recruitment through:		
Treating psychiatrist, El Sauce Hospital	56	58
Social worker, El Sauce Hospital	19	17
Psychiatrist with forensic functions, El Sauce Hospital	19	25
Treating psychiatrist, child-adolescent mental health center	6	-
Place of interview		
Ambulatory facilities El Sauce Hospital	62.5	42
Participant's home	25	42
Child and adolescent mental health care center	6	-
Telephonic	-	8
Others	6	8
Relationship between supporter and mother		
Mother	25	25
Husband/cohabiting partner	19	25
Eldest daughter	12.5	17
Father	12.3	17
Sibling (brother)	6	8
Grandmother	6	8
Does not have	12.5	-

b. Region of Granada, Spain

In Granada, a total of twelve mothers with schizophrenia and related disorders were interviewed. Differing from Mendoza, recruitment in Granada was fully done through community mental health units (See Table 5). Although other professionals were asked to identify potential participants, the task was assumed by the nurses that coordinate the mental health care teams.

Encounters with participants took place in participant's homes, in different community mental health centers and in an office of the University of Granada. One interview with a mother was conducted by phone because of her busy working schedule. One interview with a caregiver was conducted by phone as well, because she had difficulties to leave her home and family obligations (See Table 5).

Similar to Mendoza, the main figures of non-formal support in daily life were mothers (50%) and husbands/cohabiting partners (25%), but mothers occupied a larger proportion than in Mendoza (50% in Granada vs 25% in Mendoza) (See Table 4 and 5).

Table 5

General interview data. Mothers and supporters, Granada (%)

	Mothers (n=12)	Informal carers (n=10)
Recruitment through:		
***Director of the USMI**[*1]*	50	60
Nurse USMC**[*2] **Zaidín	25	20
Nurse USMC**[*2] **Cartuja	17	20
Nurse USMC**[*2] **Atarfe	8	-
Place of interview		
Participant's home	42	30
USMI	17	40
USMC Zaidín	17	-
***UGR** [*3]*	17	20
Telephonic	8	10
Relationship between supporter and mother		
Mother	50	60
Husband/cohabiting partner	25	30
Sibling (sister)	8	-
Others (uncle, maternal side)	8	10
Does not have	8	-

[*1] USMI (Unidad de salud mental infantil, Child and adolescent mental health unit),; [*2]USMC (Unidad de salud mental comunitaria, Community mental health care unit); [*3] UGR (University of Granada)

4.1.2. SOCIO-DEMOGRAPHIC CHARACTERISTICS

a. Group of mothers in the regions of Mendoza and Granada

As shown in Table 6, most mothers with SMI in Mendoza were between 40-49 years old and had an average of 2 children per woman (SD 1,15, Median 2, Min 1, Max 5). Children were of several ages, from a minimum of 1 to a maximum of 38 years. Nonetheless information about mothering experiences was only referred to children under 18 years of age. The number of women that were married or cohabiting with a partner was lower than in Granada (25% vs. 50%) and most were separated/divorced (43.75%) or single (31.25%). Mothers in Mendoza tended to be involved in less traditional type of families than women in Granada, five had children from different partners and three had some children that did not live with them but with their ex partners. In Mendoza, half of mothers lived in their parental homes with mother and/or father, and sometimes siblings.

In Granada mothers tended to be younger than in Mendoza, mostly between ages 30-39. Most were married or cohabiting with a partner (50%) and one was about to do so soon. From the rest, 33% were separated and 16% were single, although they referred to have lived for a short period of time with the father of children. In Granada, women had an average of 1.58 children per woman (SD 0.79, Median 1, Min 1, Max 3) and children were of ages 2 to 17 years. In Granada, most mothers lived with their partners, one lived alone with her child, and the rest with their families of origin. In most cases the mother stayed with the family of origin or moved with them because she needed support. In one case, it was the figure of support that was in need of housing and moved in with the mother and her family. Finally, one mother lived with the figure of support intermittently, during moments of psychotic crisis.

Table 6

Socio-demographic characteristics- Age, civil status and family composition. Mothers, both sites of study (%)

	Mothers Granada (n=12)	Mothers Mendoza (n=16)
Age : Mean (sd); Median, Min-Max	37.5 (6); 38.5; 28- 46	39.3 (8.2); 40.5; 26- 59
Civil status		
Single	17	31
Married/cohabitating	50	25
Separated/ divorced	33	44
Parity		
Primiparous	58	44
Multiparous	42	56
Age of children		
0-5	10.5	15
6-12	42	28
13-17	47	19
18 or older	-	37.5
Group of cohabitation		
Mother and/or father, and children	25	50
Husband/partner and children	42	25
Alone with one or more children	10.5	25
Others	10.5	-

Educational level tended to be higher in Mendoza, with more women having attended secondary school than in Granada. Nonetheless in Granada the proportion of women with tertiary education was higher than in Mendoza (25% vs 6.25%) (See Table 6).

Regarding work and occupation, in Table 6 we can observe that only one fourth of mothers with SMI in Granada were actively working at the moment of interview, and another fourth were unemployed and looking for a job without success. Other fourth part were occupied

with studying or taking care of home and family. The last fourth of mothers in Granada considered themselves not to be able to work because of a long lasting mental illness and were receiving a disability pension. From the unemployed women, two have been recently working in temporal or part-time jobs, mostly in cleaning or caring for elderly. They could get their work with help and support of social services (through job insertion programs) or through arrangements with caregivers.

In Mendoza, most mothers with SMI were not working and almost all of them were receiving or about to receive a disability pension due to long lasting mental illness. Half of these mothers used to have a permanent job in the past, in various areas like education, administration, commerce, industry and agriculture. The rest used to work in domestic employment or in temporary jobs, and three never worked or only worked doing household (See Table 7). Among mothers in Mendoza that were not receiving a disability pension, only one was working, and she did it in a family business supported by her family. Another was taking care of family and house, and three were unemployed.

Table 7

Sociodemographic characteristics- Education and work. Mothers, both sites of study (%)

	Mothers Granada (n=12)	Mothers Mendoza (n=16)
Educational level		
Primary education	67	50
Secondary education	8	44
Tertiary or university education	25	6
Working status		
Unable to work because of long lasting illness	25	69
Unemployed	25	19
Employed or having an autonomous job	25	6
Student	8	-
Taking care of family and house	17	6
Last employment*		
Professional/managerial/skilled manual areas	17	12.5
Semiskilled/unskilled areas	58	37.5
Temporary jobs	-	19
Never employed	-	19
Time from last employment*		
In the last year	17	6.25
1-5 years	8	31
6-10 years	17	19
11 years or more	44	19
Disability pension		
Yes	25	75
No	75	6
In progress		19

Only applies to participants that were not working at the moment of data collection.

Participants of Mendoza lived in various zones of the metropolitan area, including Guaymallén, Luján, Las Heras, Godoy Cruz and Maipú. Some lived outside the metropolitan area, in the municipalities of Lavalle, San Martín and Junín. In Granada participants lived in different regions of the metropolitan area, including the center, Maracena, Bedicina, Cenes de la Vega, Bea de Granada, Albolote, Atarfe, Illola, Peligros and Ogíjares. Most participants from both places were living in houses of own or family property (See Table 8).

As shown in Table 8, more than half of participants in both regions recognized to live without economic difficulties and most could face monthly needs regarding food, clothing and payment of bills. Around four in ten participants had economic difficulties, but only one mother in each country expressed these difficulties to be severe causing them problems to cover basic needs regarding food, clothes and housing. Two families in Granada and one in Mendoza were severely affected by payment of credits, which consumed a high proportion of their incomes.

Table 8

Sociodemographic characteristics- Housing and Economy. Mothers, both sites of study (%)

	Mothers Granada (n=12)	Mothers Mendoza (n=16)
Type of housing		
Own or family's property, without debts	42	44
Own or family's property, with debts	33	25
Rented	17	12.5
Others (borrowed, occupied)	8	19
Presence of economic difficulties		
Very good standard of living	8	6
Good standard of living	50	50
Economic difficulties are present	33	37.5
Many economic difficulties are present	8	6
Needs of food and clothing		
Always satisfied	67	75
Often satisfied	25	6
Sometimes satisfied	-	19
Never satisfied	8	-
Payment of bills		
Without difficulties	50	69
With very little difficulties	25	19
With little difficulties	8	12.5
With much difficulties	8	-
Does not know	8	-
Total monthly home income		
Mean (sd); Median, Min-Max	1504,45 (872); 1835;	6100 (6363); 4200;
(in argentine Pesos and Euros)	483- 3125	2000-28000

b. Group of informal carers in the regions of Mendoza and Granada

As show in Table 9, Informal carers in Mendoza were equally distributed by sex, while in Granada 60% were females and 40% males. Half of caregivers in both regions were age 60 or older, with a mean of 52.9 in Mendoza and 58.5 in Granada. In both regions, most were married or cohabiting with a partner, and more than half were living with the mother with SMI. This proportion was higher for caregivers in Mendoza than in Granada, reaching 83%. In Mendoza, most families were living together in the same house, except one family in which mother and figure of support had separated and independent houses in the same piece of land. The rest of figures of support were living with their own partner or partner and children, in different neighborhoods than the mother with SMI.

Table 9

Socio-demographic characteristics- Age, civil status and family composition. Informal carers, both sites of study (%)

	Supporters Granada (n=10)	Supporters Mendoza (n=12)
Sex		
Female	60	50
Male	40	50
Age		
Mean (sd); Median, Min-Max	*58,5 (13); 60; 33- 73*	53 (15,7); 60; 18- 67
Civil status		
Single	-	8
Married/cohabitating	90	67
Separated/ divorced	-	17
Widow	10	8
Group of cohabitation		
With the mother with SMI and her children	60	83
Others	40	33

Educational level and working characteristics of caregivers are shown in Table 10. It can be highlighted that the educational level was similar in both regions, with most caregivers having primary level of education. Regarding work, the proportion of caregivers that were actively working was higher in Mendoza than in Granada, were most were taking care of family and home. In addition to the mother with SMI, four figures of support in Granada were taking care of other family members with physical illnesses or with housing or economic needs. In Mendoza, two figures of support assumed day to day care of other family members with chronic illnesses besides de the mother with SMI, including other family members with severe mental or physical illnesses. Other severe illnesses with need

of permanent care were present in two families in Mendoza, but in these cases other family members were responsible for day to day care.

Table 10

Sociodemographic characteristics- Education and work. Informal carers, both sites of study (%)

	Supporters Granada (n=10)	Supporters Mendoza (n=12)
Educational level		
Primary education	50	67
Secondary education	20	17
Tertiary or university education	20	17
No formal education	10	-
Working status		
Employed or having an autonomous job	10	34
Temporary jobs	-	8
Taking care of family and house	40	25
Student	20	8
Retired	20	
Unemployed	10	8
Unable to work because of long-lasting illness	10	-
Last employment*		
Professional/managerial/skilled manual areas	30	8
Semiskilled/unskilled areas	40	25
Temporary jobs	-	-
Never employed	20	17
Time from last employment*		
In the last year	-	17
1-5 years	10	8
5-6 years	10	-
6-10 years	20	-
11 years or more	30	8

Only applies to participants that were not working at the moment of the data collection.

Caregivers in Mendoza lived in various zones of the metropolitan area, including Guaymallén, Luján, Las Heras, Godoy Cruz and Maipú. Some lived outside the metropolitan area, in the municipalities of Lavalle, San Martín and Junín. In Granada participants lived in different regions of the metropolitan area, including the center, Maracena, Bedicina, Cenes de la Vega, Bea de Granada, Albolote, Atarfe, Illola, Peligros and Ogíjares. Regarding housing, in both regions participants lived in own or family properties (See Table 11). In both regions, most caregivers identified their standard of living as good, although economic difficulties were present with different severity in more than 30% of cases (See Table 11).

Table 11

Socio-demographic characteristics-Housing and economy. Informal carers, both sites of study (%)

	Supporters Granada (n=10)	Supporters Mendoza (n=12)
Type of housing		
Own or families property, without debts	70	50
Own or families property, with debts	10	25
Rented	10	17
Others (borrowed, occupied)	10	8
Presence of economic difficulties		
Very good standard of living	-	8
Good standard of living	70	50
Economic difficulties are present	20	25
Many economic difficulties are present	10	17
Needs of food and clothing		
Always satisfied	80	58
Often satisfied	10	25
Sometimes satisfied	-	8
Never satisfied	10	8
Payment of bills		
Without difficulties	60	58
With very little difficulties	20	25
With little difficulties	10	8
With much difficulties	10	8
Total monthly home income		
Media (sd); Median; Min-Max (in argentine Pesos,and in Euros)	1370 (865); 1360; 483- 3125	6980 (6945); 5250; 515- 28000

4.1.3. CLINICAL ASPECTS

Clinical aspects are shown in Table 12. In both regions, the most frequent diagnosis of mothers with SMI was schizophrenia, followed by non-specified, non-organic psychosis in Mendoza and psychotic episode in Granada. Onset of illness, according to data provided by participants, was later for women in Granada than in Mendoza, with a mean age of 30.45 vs. 26.3 in Mendoza. In both regions illness started after having children for most women, while in Mendoza more started during pregnancies or postpartum periods when compared to mothers in Granada. In both regions mothers presented similar results in personal and social performance measured with PSP scale, with a slightly lower score among mothers in Mendoza (66.2 in Mendoza vs 69 in Granada). This punctuation corresponds to a level where difficulties are apparent, but not serious, in one or more areas of selfcare, personal and social relationships or habitual social activities, or mild disruptive or aggressive behaviors are present (Garcia-Portilla et al., 2011). The most important difference among both groups refers to the type of treatment received, since more than 90% of mothers in Granada received treatment in community mental health

care centers, while more than 81% of mothers in Mendoza received mental health care in ambulatory services of a traditional specialized psychiatric hospital.

Table 12
Clinical aspects. Mothers, both sites of study (%)

	Granada (n=12)	Mendoza (n=16)
Diagnosis (ICD-10)		
Schizophrenia (F20)	58	75
Psychotic episode (F23)	25	-
Non specified, non organic psychosis (F29)	8	25
Paranoid delusional disorder (F22.0)	8	-
PSP		
Media (sd); Median; Min-Max	69 (20); 75; 35-89	66 (13); 68.5; 34-80
First symptoms (illness onset)		
< 21	8	25
21-30	33	37.5
31-40	58	25
> 40	-	-
No information	-	12.5
Illness started		
Before having children	25	19
During pregnancies	17	12.5
During postpartum	8	25
After having children	50	37.5
No information	-	6
Place of treatment		
Psychiatric hospital (ambulatory services)	8	81
Community mental health centers	8	6
Partly private	8	12.5

4.1.4. CONCLUSIONS ABOUT THE SECTION SOCIO-DEMOGRAPHIC AND CLINICAL CHARACTERISTICS OF PARTICIPANTS

Participants from all groups were living in metropolitan areas of Mendoza and Granada, and were recruited through the mental health care services the mothers were attending. In Mendoza, most participants were contacted through their treating psychiatrist, while in Granada recruitment was done through the nurses of the mental health care teams or through the director of the child mental health care unit of the region of Granada.

Mothers in Mendoza were of older age, had higher number of children and more were single or separated from their partners when compared to the group of mothers in Granada. As well, families in Mendoza tended to have a less traditional conformation than

families in Granada, with more blended families and more mothers living with their children in their parental homes. Educational level tended to be higher in Mendoza, although in Granada there were more women that reached tertiary education. In Granada, more women were working and less were receiving a disability pension than mothers in Mendoza. More than half of participants in both regions categorized themselves as living without economic difficulties. Nevertheless, around four in ten families in both regions expressed to have economic difficulties, which were severe in the minority of cases.

Two mothers in Mendoza and one in Granada expressed not to have a figure of support in their daily lives. The rest counted with one or more figures of support providing care in their daily lives and being involved in their parenting tasks. Caregivers in Mendoza tended to be slightly younger than in Granada, with a mean age of 53 years, compared to 60 years in Granada. In Mendoza caregivers were equally distributed by sex, while in Granada there were more women acting as main caregivers than in Mendoza. In both regions of study, caregiving was most frequently assumed by a member of the family of origin, followed by partners. Most supporters in both regions were living with the mother with SMI and their children, although the percentage of caregivers in this situation was lower in Granada than in Mendoza. Most caregivers were married or cohabiting with a partner in both regions, but in Mendoza were more single or separated supporters than in Granada. In Mendoza, caregivers had lower levels of education and more were employed or had employment in the last year when compared to their counterparts in Granada. In Granada, there was a higher percentage of caregivers that were taking care of family and house, were studying or were retired. With respect to economic status, most caregivers in both regions expressed to have good standards of living. The percentage of supporters with economic difficulties was slightly higher in Mendoza than in Granada (42% vs. 30%).

4.2. RESULTS: EXPERIENCES OF MATERNITY

4.2.1. STRENGTHS AND POSITIVE ASPECTS OF THE MATERNAL EXPERIENCE

As can be seen in Table 13, maternity was highly valued by the vast majority of mothers in both sites of study. They considered it to be a ***beautiful, joyful and very emotional experience***, which was faced with much love. Especially among mothers in Granada, maternity was regarded as a very important desire, activity, priority and even need in life.

> *'Being a mother is a precious experience… We were looking for him, and when he came… I was so happy! I don't know. It is a big joy' (Quote 3:66, mother with SMI, Granada)*

Around one third of mothers in both sites considered their ***children as motor of their lives***, a source of motivation, emotional support and joy, and their reason to live, feel good and recover.

> *'My children are the motor of my life… If they were not here I would not be here the way I am now, or maybe I would not even be here… They are a support for me' (Quote 2:96, mother with SMI, Granada*)

Two mothers, one in each site of study, did not have ***any positive expressions*** about their maternal experience. On the contrary they complained extremely about their child and felt burdened and tired by childcare.

> *'I need her to change, to change! … because it is so tiring what she does…' (Quote 53:28, mother with SMI, Mendoza*)

Regarding their parenting abilities, 75% of mothers in Granada and half of this amount in Mendoza felt ***confident and highlighted their strengths regarding childcare***, feeling capable of taking care and covering the needs of their children during stable moments, and some even during problematic situations. More specifically individual mothers talked about how they could solve problems without difficulty, adequately organize themselves regarding childcare, educate and set adequate limits to children and enjoy them without stress.

> *'The first months after he was born were as if I had done it all my life, like an instinct' (Quote 3:9, Mother with SMI, Granada)*

Table 13

Positive side of maternal experiences. Mothers, both sites of study

	Granada (n=12)	Mendoza (n=16)
Beautiful, joyful, emotional experience	11	15
Very important desire, activity, priority, need in life	7	3
Children motor of life, source of motivation, emotional support and joy	4	4
Confident about own parenting abilities	9	6
No positive aspects	1	1

As shown in Table 14, most caregivers in both sites of study also acknowledged some ***strong parenting abilities*** in mothers with SMI. In both regions participants identified similar themes and talked about them with similar frequencies, except for the ***loving and caring attitude*** of mothers, which was highlighted with more frequency in Mendoza than in Granada. Around 40% in both places highlighted how mothers managed to ***adequately care for children*** in general terms. Others specified the areas in which mothers could take care of children without troubles, especially referring to basic ***instrumental aspects of childcare***. Frequently supporters associated mothering to the ***ability to deal and organize household tasks***, and highlighted how mothers dealt with this in an adequate way. With less frequency, in both places some supporters mentioned how mothers placed ***children as a priority in their lives***, how they were ***attentive to child needs***, ***looked for help or advice*** when they had troubles, provided ***education and advice to children*** and ***functioned independently in mothering tasks***. One thought the mother could do more than what she recognized.

Table 14

Strengths in parenting of mothers with SMI. Supporters, both sites of study.

	Granada (n= 10)	Mendoza (n= 12)
Loving and caring with children	2	6
Children are a priority in life	1	2
Adequate for childcare in general	4	5
Adequate instrumental childcare	4	6
Attentive to child needs	2	4
Adequately perform household tasks	3	4
Others	2	5

4.2.2. NEGATIVE ASPECTS OF THE MATERNAL EXPERIENCE

Most mothers with SMI recognized maternity to be an ambiguous experience which conjugated positive and negative aspects. Along with positive aspects, most mothers in both places talked about negative facets of their parenting experiences, including different type of feelings and difficulties (See Table 15) Several participants in both sites talked about experiencing ***strong negative feelings about being a mother***, with higher frequency in Granada than in Mendoza. In Granada, more than half of participants expressed to feel overloaded or overwhelmed by childcare. This was only expressed by one mother in Mendoza, while many talked about not feeling happy and having difficulties to adapt to the idea to have a child and take care of him/her. Difficulties to adapt to the idea of having a child was related by some mothers to unplanned pregnancies or to the appearance of depressive or psychotic symptoms after birth.

> *'I have more responsibilities since I have children, they overwhelm me… both children, they overwhelm me' (Quote 1:78, mother with SMI, Granada)*

> *'At the beginning I did not want to know anything related to him… I wanted to give him away' (Quote 49:15, Mother with SMI, Mendoza)*

Other negative feelings included guilt and sadness, anxiety and anguish, fear, jealousy, and the feeling of being a 'burden' for their children. Some mothers thought that guilt and sadness appeared because they were not able to adequately take care of their children. Fear was mainly associated to the possibility of mental illness impeding them to take care of children, but also to the possibility of having children taken away and to worries about children's safety. Experiencing these feelings was considered by some as a factor that worsened their mood, increasing difficulties to take care of children, creating a vicious circle they could not break.

> *'I am afraid that they will take him away, my parents… because I am not responsible for him… I am not the one that takes him to school, that is economically responsible for him… All that makes me feel bad…' (Quote 11:55, Mother with SMI, Granada)*

Other frequent difficulties in parenting expressed by mothers in both sites of study were regarding ***discipline and control of children's behavior and difficulties in the interaction with children***. Children ignoring or disobeying them was expressed by half of mothers in Mendoza and almost half of mothers in Granada. Especially in Granada,

mothers tended to consider disobedience as a characteristic of children themselves, describing them as rebel, jealous, defiant, capricious, stubborn or difficult. Less frequently, some mothers related disobedience of children to own permissive and indulgent attitudes, own difficulties to put limits to children or having no authority on children.

> *'I scream a lot to my child, because she does not pay attention to me! She goes outside and doesn't do what I say' (Quote 43:91, mother with SMI, Mendoza)*

As well, several mothers expressed to have ***difficulties in the interaction with their children***. They frequently felt irritated, nervous and tired by children, mostly when they were disobedient. Some talked about how they frequently had excessive reactions in these situations, which included screaming and in one case, use of physical violence as disciplining measure. Others talked about having difficulties to control intrusive or overprotective attitudes with children. Finally, in Granada some mothers talked about having rejected their children for periods of months or years, during which they delegated childcare to figures of support.

> *'He is a very bad educated child… he has very bad customs, very capricious… and he is very dominating… and I am worried, and… a little afraid of him… I am on pills because of him' (Quote 20:22, Mother with SMI, Granada)*

Expressed by half of mothers in Granada, were ***difficulties to offer adequate material conditions to their children***, especially economic resources but also a safe and adequate environment for a child. In the moment of the interview, one participant was in high danger of having her children taken away because of severe economic difficulties. These concerns were less frequently expressed in Mendoza, where 19% of mothers talked about worries and hard moments related to economic difficulties and fears they might not be able to cover all material needs of children.

> *'To maintain the house, the child… his parents help us a little. But I don't pay anything, and it hurts me a bit…' (Quote 18:89, Mother with SMI, Granada)*

In Mendoza, almost half of mothers expressed ***not knowing how to deal with some issues related to childcare***, like sleeping or eating problems of their children, or more specific problems like hyperactivity. In a similar way, some mothers in Granada talked about difficulties to react when a problem arises, and to accept children's problems.

> *'She does not eat anything… and I am worried… and feel bad, because I don't know how to deal with it…' (Quote 30:38, Mother with SMI, Mendoza)*

Less frequently, one in four mothers in Mendoza talked how they **perceived *child raising and care to be difficult in general*,** and in Granada one in four ***felt they lacked strength and abilities to be able to take care of children***.

Finally, issues mentioned by individual mothers in Mendoza included mothering becoming an exclusive activity that requires all her time, mothering 'confining' he mother to her house in solitude with her child, or being a disappointing experience since she could not form a 'normal' family. One expressed fears and uncertainties about delivery and about her capability of taking care of her child. Other talked about frequent accidents with child in the home having difficulties in paying attention to child, having difficulties to give the stimulation the child was needing, having difficulties to set priorities, like dedicating more time to cleaning than to take care of her child.

Table 15

Negative side of maternal experiences. Mothers, both sites of study

	Granada (n=12)	Mendoza (n=16)
Difficulties to control children's behavior and conduct	5	8
Negative feelings	*10*	*8*
Feeling overloaded and overwhelmed	*7*	*1*
Guilt and sadness	*4*	-
Fear	*2*	*1*
Others: anguish, jealousy, burden	*4*	-
Not happy about having a child	-	*5*
Difficulties in the interaction with children	6	6
To feel and react irritated and nervous by children	*3*	*4*
No desire to be with children	*4*	-
Being aggressive	*2*	*3*
Being overprotective or intrusive	2	*2*
Lack of adequate material conditions for child raising and care	6	3
Difficulties to face problems related to childcare	2	7
Difficult in general	-	4
Others	5	3

As can be seen in Table 16, most figures of support talked about diverse difficulties they observed in mothers with SMI in different areas of childcare and raising. Some were very explicit and open while others did not talk about this when asked directly, but spontaneously addressed some in the course of the interview. Five supporters did not express any difficulties in parenting in mothers with SMI, but some of them did stress the need of mothers to have support or talked about having a difficult situation regarding parenting, without wanting to express in more detail why they said so.

Differing from mothers, the main difficulty supporters of both places observed was in ***mother-child interactions***. These difficulties were described with much more detail than mothers themselves, and were mentioned by half of caregivers in Granada and 67% in Mendoza. The most common concern in this respect was about mothers that frequently reacted arbitrarily or with irritation, aggression or threats towards their children. A few reached the point of using physical aggressions. Another common concern was that mothers frequently avoided to spend time and assume responsibility with their children. Others considered mothers had inconsistent attitudes towards children, like making inappropriate demands, having changing attitudes, and introducing differences between children. Other problems expressed with less frequency in mother-child interactions included mothers acting as children with their children or inverting roles with children who sometimes took responsibility for her wellbeing, being too sensitive to criticism of their children, being overprotective and having difficulties to stimulate them.

> *'She fights a lot… all the time. She is not calm and doesn't let us be calm either…' (Quote 38:28, supporter, Mendoza)*

> *'When she interacts with L. it is like a game. She wants to have complicity with the child… but a very… childish complicity… very basic…' (Quote 12:120, supporter, Granada)*

Another common area of concern was ***discipline***, with a slight higher frequency in Granada than in Mendoza. Supporters tended to associate difficulties in discipline with characteristics of mothers, which were described as lacking authority, having difficulties to set limits and control children's behavior, being too permissive and being easily manipulated by children. On the contrary, one supporter in Granada considered the mother to be too strict with her child.

> *'The child does not respect her… the child, with six years of age, was the one ruling the house…' (Quote 16:77, supporter, Granada)*

Around 30-40% of supporters in both places expressed worries about mothers being ***negligent*** in some aspects of childcare, sometimes putting the child at risk. They talked about negligence in providing proper dressing and feeding, about leaving child locked in the house, taking the child to dangerous places or letting the child be in dangerous contexts. Besides this, two supporters in Mendoza were worried about mothers possibly hurting their children physically and were afraid to leave them alone with her. Some supporters additionally explained that mothers were not aware of own role and

responsibility with children, of own difficulties, of consequences of their actions on children and of children's needs.

> *'I am not sure if I can leave her here because maybe she will get bored and leave, at any time… and after a while she calls me, tells me she is in that place… she has done it a few times… What are you doing there, at that time, with our child?' (Quote 40:70, supporter, Mendoza)*

> *'She leaves! gets rid of the problem, gets rid of responsibility and leaves me with the responsibility with the child' (Quote 12:124, supporter, Granada)*

In Granada, one third of supporters talked about mothers ***lacking adequate material conditions*** to raise a child, including the possibilities of maintaining a safe environment, maintaining hygiene, or counting with adequate economic resources. This was also the case of mothers in Mendoza, but supporters did not identify it as a difficulty related to parenting. A similar number of caregivers talked about mothers having ***difficulties in the organization of children's activities and daily routines,*** and less frequent observations included ***difficulties to put children as a priority***, and mothers ***lacking preparation*** to take care of a child.

Table 16

Difficulties in parenting of mothers with SMI. Supporters, both sites of study

	Granada (n= 10)	Mendoza (n= 12)
Difficulties in mother- child interaction:	5	8
Mothers being irritable and sometimes aggressive	*5*	*4*
Avoid time and responsibility with child	*3*	*3*
Inconsistent attitudes	-	*3*
Acting as children or inverting role with child	*2*	-
Too sensitive	-	*2*
Difficulties to stimulate the child	*1*	*1*
Overprotective	-	*1*
Difficulties in disciplining children:	6	6
Lack of authority and difficulties to control child behavior	*5*	*3*
Too strict with child	*1*	-
Negligent attitudes	3	5
Risk of hurting the child	-	2
Lack of adequate material conditions	3	-
Difficulties in the organization of activities	3	2
Difficulties to put children as a priority	2	1
Not be prepared to take care of a child	-	2

4.2.3. CONCILIATION BETWEEN MENTAL ILLNESS AND MATERNITY

In both places, participants of the study talked about the way in which mental illness could influence maternal experiences. It is worth noticing that participants in both places talked about other personal characteristics of mothers, their children and their contexts that could influence their maternal experiences besides the fact of having a mental illness. These characteristics are summarized in Table 17. In Mendoza, participants tended to talk more about the influence of context in parenting, while in Granada they talked with higher frequency about characteristics of children and mothers themselves that could affect parenting.

Table 17

Determinants of maternal experiences. Mothers and supporters, both sites of study

	Granada		Mendoza	
	Mothers (n=12)	Supporters (n=10)	Mothers (n=16)	Supporters (n=12)
Personal aspects*1:				
- ***Mental illness***	*12*	7	*16*	11
- ***Age***	*4*	1	-	-
- ***Experience in childcare***	-	-	*3*	-
- ***Others: unplanned pregnancies, having lost a child before, character, physical illness***	3	2	-	-
Contextual aspects*2:	2	1	7	2
Characteristics of children*3:	5	5	4	-

1 Older age when having a child, having experience in childcare and having a calm and patient character were considered positive influences for childcare. Young age when having a child, having a chronic physical illness, having had unplanned pregnancies or having lost a child before were related to negative mothering experiences.

2 Being alone to raise the child, having non-supportive social relationships, absence of the father, having a threatening or violent context, having economic problems or marital problems

2 Children with behavioral problems, autism, cognitive impairments; having more than one child; periods of higher demand like starting to walk, scholar period or adolescence.

Yet, mental illness was the determinant of maternal experiences that was mentioned with higher frequency among all groups of participants of the study. They not only talked about negative but also positive influences of mental illness on maternity, about the influence of having children on the evolution and treatment of the maternal mental illness, and about consequences on children. These aspects will be explained in the following lines.

4.2.3.1 Influence of mental illness on maternity during moments of stability of mental illness

Regarding the possibility of mental illness to influence participants in their parenting tasks and experiences, most mothers and supporters in both places considered that ***mental illness interfered with parenting and caused most of the above-mentioned difficulties in parenting***. As shown in Table 18, *symptoms like depressive mood, tiredness and lack of will, as well as sedation and tiredness caused by medication*, were considered as the most frequent aspects of illness and its treatment that caused difficulties to keep up with children's activities and needs.

> *'I am not the one I used to be… sometimes my child does his homework and I sleep. Sometimes we don't go out because I stay home sleeping… there are things I used to do that I can't anymore.' (Quote 2:97, mother with SMI, Granada)*

With less frequency participants mentioned *other symptoms* that could affect parenting, like high levels of anxiety, irritability, lack of tolerance and sensitivity, episodes of loss of consciousness or panic attacks and chronic productive symptoms, especially delusions and perceptive disturbances.

> *'I don't want anything to happen to him… I don't trust people… because in the news they always show about sexual abuses or things like that… in am very sensitive regarding that topic… and it creates me a paranoia, and I get jealous, I don't want anyone to spend time with him…' (Quote 11:26, Mother with SMI, Granada)*

Supporters additionally mentioned *cognitive and thinking impairments and intellectual difficulties* of mothers. For example, they talked about mothers easily forgetting things, not being able to concentrate on one activity, having difficulties to solve problems, not being coherent when talking to children, not thinking and acting rationally or having difficulties in comprehension.

> *'I used to talk to children to explain them one thing, another… because my daughter, poor of her, she speaks nothing coherent…' (Quote 46:133, supporter, Mendoza)*

Others mentioned a lack *of personal characteristics and abilities* which they considered necessary for adequate parenting, like lack of flexibility, lack of productive activity, having

a mentality of a 'child' or 'younger person', and having difficulties to control disruptive behaviors in front of the child.

> *'She is very strict, too rigid in the education of the child' (Quote 24:32, supporter, Granada)*

Some mothers, with higher frequency in Mendoza than in Granada, additionally talked about how *stigma related to mental illness* affected their experiences as mothers. They felt judged and blamed, or feared that mental illness per se would make them incapable of taking care of her children.

> *'Life has taken so much from me… maybe because of the illness, I don't know… It took away my children, not physically, but they distanced themselves from me… and it hurts, it annoys me…' (Quote 33:84, mother with SMI, Mendoza)*

Finally, two mothers in Granada thought of ***mental illness as a positive influence for parenting***, because it improved understanding and empathy with their mentally ill children, or because it made the mother more aware of her role and improved the interaction with child and family in general. Worth to mention is that this participant was the one with shorter evolution of illness (one year), while the rest had a history of several years of evolution.

Table 18

Conciliation between maternity and mental illness: Influence of mental illness on maternal experiences in the long term. Mothers and supporters, both sites of study

	Granada		Mendoza	
	Mothers (n=12)	Supporters (n=10)	Mothers (n=16)	Supporters (n=12)
Symptoms associated to mental illness	6	4	9	6
Medication that causes sedation and tiredness	5	2	5	3
Stigma associated to mental illness	2	1	3	-
Lack of personal characteristics necessary for parenting	-	5	-	6
Others: higher empathy, more awareness of own responsibilities with child and family	2	-		-

All participants made a balance between mother's difficulties, strengths and supportive resources, producing an overall valuation of the mother's capability to take care of their children in the long term.

Despite the interference of mental illness in parenting tasks, all women but two (one in each place of study), felt they were **still capable of taking care of their children in the long term**.

'Sometimes we must become strong, and think about our children that need us… they give me the strength to keep going every day. And it is possible, you can, you can overcome this' (Quote 51:55, mother with SMI, Mendoza)

On the contrary, one mother in each site of study, felt they were **not capable of taking care of their children** due to the difficulties brought by the mental illness, never, or during some periods. One of them considered the mental illness made her lose her maternal instinct.

'I lost my mind and did not get it back… well, yes, I did get it back, but I did not recover my maternal instinct' (Quote 3:58, Mother with SMI, Granada)

With a different perspective than mothers, supporters tended to incline the balance between weaknesses and strengths regarding the maternal role and functions to the weak side. Most supporters thought that difficulties in parenting abilities were severe but they considered **mothers could take care of her children during moments of stability as long as they had intensive support in that area**.

'She does not have that ease she should have with her children… She does it all, does it, but always with the support of her husband…' (Quote 5:18, supporter, Granada)

On the contrary, few figures of support in both places considered mothers with SMI to be **incapable of taking care of their children**, one even seeing her as a disruptive figure for children. One caregiver remarked the drastic change that the mental illness introduced into the mother's abilities to take care of the child, being very concerned and involved in childcare before the onset of mental illness.

'We are not all prepared… She wanted to have a child, but I think she was never prepared to have the child… to take care of him, give him what he needs.' (Quote 54:66, supporter, Mendoza)

With a completely different view and coinciding with the mothers they supported, some caregivers (two in Granada and three in Mendoza) did not see **any limitations in the mothers with SMI to take care of their children** in a way they considered appropriate. One even perceived the mental illness as a process of learning that improved mother-child interaction and family relationships.

'There was no problem with children… she adapted well again… it is like nothing happened. You cannot notice there was a break…' (Quote 27:10, supporter, Mendoza)

4.2.3.2. Influence of mental illness on maternity during psychotic episodes

Participants of all groups described the appearance of symptoms of different quality during psychotic breakdowns, as well as a much more severe affection of parenting capacities which required a reorganization of tasks between mothers and supporters. Half of mothers in Granada and one third in Mendoza, talked about diverse type of ***productive psychotic symptoms and behavioral disturbances*** that they had experienced during psychotic breakdowns and affected their parenting. These included suicide attempts, auditory hallucinations, paranoid delusions or intrusive ideas which sometimes were related to their children, for example when delusions included a threatening content related to their children.

'I started to feel bad again while I was in the hospital… I started to think they would take my child away… and other stuff, all related to my child…' (Quote 14:10, Mother with SMI, Granada)

Two mothers in Granada mentioned ***children sharing the perception of some symptoms*** as auditory hallucinations, and other mothers described how ***children got nervous, scared or angry*** because of their symptoms or because they were separated from her.

'I had such a strong psychotic breakdown, so strong that my children were crying, they did not understand what was happening with their mum' (Quote 13:33, Mother with SMI, Granada)

Others talked about ***not recognizing or rejecting their children*** during these moments, while the majority described to have had behaviors of protection towards children when experiencing these symptoms. None expressed to have had aggressive behaviors towards children, on the contrary to what some figures of support expressed.

'I don't remember anything from the breakdown, but my husband told me that I did not recognize my daughter… neither my family…' (Quote 43:8, Mother with SMI, Mendoza)

Supporters in both places expressed additional difficulties regarding the ways in which women treated their children during the psychotic episode. In both places supporters described how mothers had become ***negligent, aggressive, rejecting or incoherent with the child***.

> *'She becomes a bit aggressive and I can't… I can't put my family at risk, to put four people at risk for one, you see? So I tell her directly, this cannot keep going, we will go to the hospital…' (Quote 52:21, supporter, Mendoza)*

One father gave the metaphor of 'oil and water', to refer to the impossibility of the mother to be near the child during the moment of crisis. Some supporters also talked about how mothers were affected by ***strong adverse effects of medication*** that made them sleep all day long or be completely inactive, sometimes for weeks or months after the episode was over.

> *'She came back home but could not do anything, she was sleeping all day!' (Quote 48:11, supporter, Mendoza)*

Table 19

Conciliation between maternity and mental illness: Influence of mental illness on maternal experiences during psychotic breakdowns. Mothers and supporters, both sites of study

	Granada		Mendoza	
	Mothers (n=12)	Supporters (n=10)	Mothers (n=16)	Supporters (n=12)
Productive psychotic symptoms and behavioral disturbances that affected mothers' parenting ability	6	8	5	9
Mothers did not recognize or rejected their children	2	5	4	4
Mothers had inappropriate attitudes towards children, becoming aggressive or incoherent	-	3	-	7
Strong adverse effects of medication turned mothers unavailable for their children	-	-	-	2
Children shared auditory hallucinations or behavioral disturbances with mothers	2	-	1	-
Children got emotionally affected by mother's symptoms or by separation from her	4	4	3	3

Almost all mothers and supporters agreed that mothers were incapable of taking care of their children during psychotic relapses. During these moments, most children stayed with their mothers but were cared by someone else. In some cases, they were separated from the mother, because she was hospitalized or because supporters wanted to avoid children to be exposed to such a dramatic situation.

'My child, she stayed with my husband's parents… but she was uncomfortable there, she noticed something was not going well' (Quote 18:50, mother with SMI, Granada)

The exception were two mothers (one in each site of study) and one supporter in Granada, that considered the mother was not affected during crisis in her maternal role and was still capable of taking care of her children. One mother described the situation as *'retaining some sanity in insanity'*, which allowed her to be aware of her children needs and take care of them.

4.2.3.3. Influence of maternity on mental illness

Participants also talked about how being a mother influenced aspects of their illness, especially their evolution, motivation to look for treatment, and possibilities of receiving care (See Table 20). Many mothers in Granada and Mendoza talked about how *having children could moderate the impact of illness on their lives*, since it gave them a motivation to recover, keep stable and overcome limitations, helped them to adopt a more organized and healthy routine or made them feel better in general.

'They keep me going. If it hasn't' been for them maybe I would not have kept going… but I have always asked God the strength to keep going for them' (Quote 8:30, mother with SMI, Granada)

On the contrary, others felt that *having children had been a negative influence on their illness.* This was because responsibilities associated to childcare could contribute to worsen some symptoms as unstable mood, anxiety and depression, aspects which were expressed with much higher frequency in Granada than in Mendoza.

'Since I had children… life changed radically. I have been bad, because I used to have up and downs, but because of children I have been worse…' (Quote 1:31, Mother with SMI, Granada)

It was also commented that having children could restrict possibilities of receiving some types of care. Restrictions in care included difficulties to be hospitalized because of having children, restrictions in type of medication that could be taken, limitations to participate in rehabilitation programs because of lack of time and limitations to look for social support given restrictions to travel.

'I cannot get hospitalized, or go to see my family… I have to stay here, with her…' (Quote 39:71, Mother with SMI, Mendoza)

Most supporters did not talk about how being a mother could affect the evolution of the mental illness, except for some caregivers in Granada who considered that having children and having to take care of them affected mothers' lives in a negative way, because it added more responsibility and problems on an already difficult situation brought by the mental illness.

'My daughter takes tranquilizers, and it does not work for her! Because she is all the time paying attention to her child that is in the street, and it makes her nervous… he is growing up and she is getting worse' (Quote 23:8, supporter, Granada)

Table 20

Conciliation between maternity and mental illness: Influence of maternity on mental illness. Mothers and supporters, both sites of study

	Granada		Mendoza	
	Mothers (n=12)	Supporters (n=10)	Mothers (n=16)	Supporters (n=12)
Positive influences on psychopathological evolution	4	-	4	-
Worsening of symptoms associated to parenthood	5	3	1	-
Restrictions to receive formal and informal care	1	-	2	-

4.2.3.4. Consequences of maternal mental illness on children

Some women talked about *the consequences that their mental illness could bring on children in the long term*, with higher frequency in Argentina than in Spain. Frequent ***negative consequences*** expressed by mothers included *worries about children having been exposed to psychotropic drugs during pregnancy.* Others felt *they were passing negative characteristics to their children*, like hypersomnia, anguish, isolation and stigma associated to mental illness. Some considered their children to have *behavioral problems* because of their mental illness, including aggressiveness and suicide attempts (See Table 21).

'When he was a baby I spent all the time sleeping… I gave him milk and then he would sleep with me… I guess he was bored…' (Quote 44:70, mother with SMI, Mendoza)

Nevertheless, most mothers did not talk about any specific problematic in children in the long term and some even highlighted ***positive consequences on children*** who became more *mature, independent and responsible*.

> *'He is very mature, he was grown up because of the illness. They say that since he has seen me with those episodes, he grew up, sometimes he acts like a dad! He takes care of me so much! (Quote 51:44, mother with SMI, Mendoza)*

The view of figures of support differed on the view of most mothers, most of them considering children to be negatively affected by the maternal mental illness in the long term. In both places supporters talked about *children suffering and being emotionally affected* because of maternal illness and difficulties. Some noticed children cried very often or were fearful.

> *'When I was going to primary school I had many problems… I was feeling bad, crying all the time. And now too, I see my dad suffers, my sisters suffer…' (Quote 38:30, supporter, Mendoza)*

Others talked about *children taking distance from mothers* and getting more attached to their father or figures of support, mainly the grandmother.

> *'The child does not want the mother to take him to school. He asks me to take him… that hurts her, of course… so I tell her that I will take him and she can go and pick him up' (Quote 54:47, supporter, Mendoza)*

A few children became aggressive and critical towards the mother and others directly avoided being at home. Others adopted more rebellious or defiant behaviors, even dropping out of school. A few supporters talked about children becoming physically sick because of negligent or violent attitudes of mother. Some observed in children some of the difficulties resembling the ones of the mother regarding social isolation, inadequate behaviors, mistrusting attitude, or having a mental illness as the mother. Others talked about children taking an adult role and having a future with the obligation of taking care of his mother.

> *'It is not only her illness… it's the child growing up with a type of education which is not… he learns to manipulate his mother… and his behavior is starting to be a bit unbalanced too…' (Quote 12:225, supporter, Granada)*

On the contrary, some supporters considered children not to be affected in the long term by the maternal mental illness and others highlighted areas were children did not become affected.

> *'The child is doing well at school… until now it is all fine with him' (Quote 31:54, supporter, Mendoza)*

Table 21

Conciliation between maternity and mental illness: Consequences on children. Mothers and supporters, both sites of study

	Granada		Mendoza	
	Mothers (n=12)	Supporters (n=10)	Mothers (n=16)	Supporters (n=12)
Negative consequences on children	3	6	6	8
Positive consequences on children	2	-	3	-
No consequences on children	9	-	6	4

4.2.4. CONCLUSIONS ABOUT THE SECTION: EXPERIENCES OF MATERNITY

In conclusion, both mothers and supporters in both sites of study found positive aspects and strengths regarding parenting of women with SMI. These were especially noticed regarding affective aspects, instrumental aspects, and the high value given to the maternal role by women with SMI. All groups of participants coincided in identifying diverse difficulties they found in parenting, especially regarding the possibilities to affront the overload of tasks, discipline, adequate interaction with children and possibilities to offer adequate material conditions for childcare. Differences in accounts were mainly observed between groups of mothers and supporters, since mothers tended to be less detailed in their accounts and identified less amount of problematic areas than supporters. Main differences among regions included a more confident attitude of mothers in Granada about their parenting abilities, when compared to Mendoza. As well, mothers in Granada tended to complain with higher frequency about different problems, and noticeably protested more about inadequate material conditions. Difficulties were mainly but not only provoked by symptoms of mental illness and adverse effects of medication. Stigma was identified by some participants as causing difficulties in parenting, mainly because it prevented mothers to openly talk about their experiences, as well as seeking and finding the needed support. The interrelation between motherhood and mental illness was complex, and even when

most considered mental illness to affect parenting and children, some participants identified positive aspects, especially regarding the positive influence of parenting for the evolution and motivation to keep stable in their mental illness. Difficulties were important enough to hinder mothers in their parenting, but most participants considered that they could be overcome or compensated through different strategies, especially having support specifically related to parenting. During psychotic breakdowns parenting was severely compromised, and support needed to be intensified. Aspects related to support in parenting will be included and extensively explained in the following sub-section.

4.3. RESULTS: EXPERIENCES OF SUPPORT IN PARENTING IN DAILY LIVES

Most participants extensively talked about support mothers received in their mothering role as well as in other aspects of their lives. Support was described as a process that involved several actors, in general including the mother as an active participant. It involved diverse activities and functions, as well as varying types of interactions and relationships between caregivers and receivers of care. These aspects will be presented in the following section, starting with the description of the primary and secondary figures of support, and their activities and functions. Following, aspects regarding dynamics and valuation of the caring process will be described.

4.3.1. ORGANIZATION OF SUPPORT AND SOURCES OF SUPPORT

As shown in Table 22, most families in both places of study organized support in mothering role and tasks around one main caregiver, counting with secondary figures of support to complement their activities. Only one mother in Mendoza counted with an **only caregiver**, that took on all functions and activities of support. Some families in both sites of study had an organization in which **many people were equally involved in mother and child's support**, so that main and secondary figures could not be distinguished. These networks were conformed by several members of own family of origin, or members of family of origin and the father of the child.

Table 22

Organization of support. All participants

	Mothers Granada (n=12)	Mothers Mendoza (n=16)
Main and secondary caregivers	9	14
Network of many caregivers equally involved	3	1
Only caregiver	-	1
No figure of support in parenting	1	2

Main caregivers were usually members of the mother's family of origin, in most cases their own mothers and sometimes father, siblings, and in one case an uncle (See Figures 4 and 5). With less frequency, it was the current husband or partner of the mother who

mainly supported her in parenting, even if he was not the father of all or some of her children. In Mendoza, two mothers counted with their eldest daughters to take the role of main supporter in parenting tasks, helping them to care of their own siblings.

Figure 4
Main figure of support. Mothers Granada (n=12)

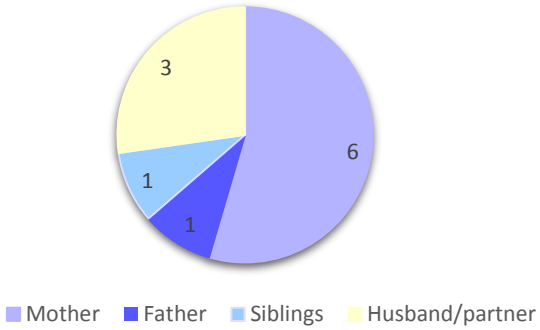
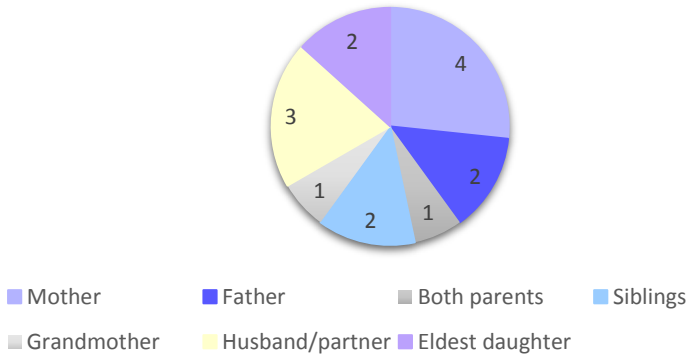


Figure 5
Main figure of support. Mothers Mendoza (N=16)



All mothers, except for one in Mendoza, counted with **secondary figures of support** providing less frequent or intense support in their mothering role and activities. These supporters constituted a network around one main figure of support and guaranteed that there would always be someone attentive to the mother and the child. It was also common that many people were involved in economic aid to the mother and her child, especially in Mendoza. Nonetheless there was no specific activity that characterized secondary figures of support, but in general were involved in complementary activities of the main caregiver. Mainly members of the mothers' family of origin were involved in this way, mainly parents, followed by siblings, and in one case in Mendoza, a cousin. Husbands or father of the child were many times considered as secondary figures of support, especially when they were separated from the mother. Also, husband's families of origin were involved in this way,

specially mothers in law. Own daughters or sons were also frequently considered as additional supporters for mothers, as well as partners of their fathers. Outside family, some women counted with support from neighbors, friends, charitable members of the community and groups of women at school or work. In one case in Mendoza the main figure of support built a network paying to neighbors and other close people to provide aid and company to the mother (See Figures 6 and 7).

Figure 6
Secondary figures of support. Mothers, Granada (n=12)

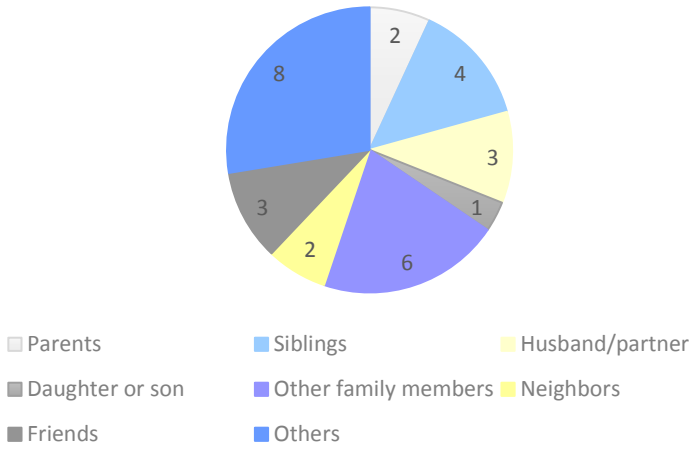
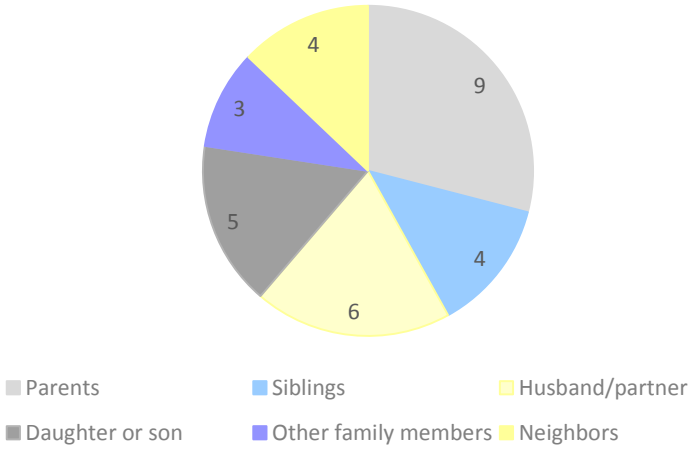


Figure 7
Secondary figures of support. Mothers, Mendoza (n=16)



Finally, a few mothers -one in Granada and two in Mendoza- considered they had no main figure of support in their mothering role at the moment of the interview. Nevertheless,

none of these mothers lacked social support in other areas of their lives. One did count with her brother to provide informal care in mental illness related issues, and two counted with family members to support them in different ways, but mothers valued their help as insufficient or disturbing. In this last case, the mother acknowledged this role to a therapeutic companion she met regularly. This figure is considered as part of the formal system of care and will be included in the corresponding section.

4.3.2. ACTIVITIES AND FUNCTIONS OF SUPPORTERS

Main figures of support performed various functions related to care of the mother and her child. Typically, participants described activities that were directly related to support in parenting, but also several other activities that indirectly but importantly influenced the mother in her parenting role. In general, these types of activities tended to be long lasting in time and provided during phases when the mother was stable.

During moments of relapse of the psychotic illness the dynamic of support varied, with modification in the type and intensity of support given. Following these characteristics, activities and functions of supporters will be presented according to the different phases of illness during which support was required, namely moments of relapse and moments of stability.

4.3.2.1. Activities of supporters during psychotic relapses

During moments of relapse of the mental illness, support varied greatly depending on the way the crisis was managed, namely care at home or hospitalization. In Mendoza, most mothers were hospitalized for periods of weeks or months (See Table 23). Half of these mothers talked about supporters taking over care of her children during moments of acute psychotic symptoms and hospitalization, as can be seen in Table 24. Half of supporters in Mendoza also narrated how they took full care of the child while the mother was hospitalized, and continued with this function for variable periods of time while she recovered. In one case, one secondary figure of support was in charge of breastfeeding the child.

> *'While I was in hospital my son stayed with my mother in law, the girl with my mother and the boy with my mother in law. My husband was going to work and she was taking care of the child…' (Quote 30:80, Mother with SMI, Mendoza)*

Less frequently, psychotic breakdowns that were not severe were managed at home in Mendoza. In these cases, families of origin took over the control of symptoms and medication.

> *'My parents decided to have a home admission, so my mum and dad took care of me and of him (the child)'. (Quote 51:28, Mother with SMI, Mendoza)*

Table 23

Management of psychotic breakdown. Mothers, Granada and Mendoza

	Mothers Granada (n=12)	Mothers Mendoza (n=16)
Hospitalization of weeks or months	-	9
Brief hospitalization followed by intense care at home	6	1
Ambulatory care	6	6

In Granada, mothers tended to receive ambulatory care during psychotic breakdowns, or hospitalization of shorter time than in Mendoza followed by intense care at home. When the mother was not hospitalized, primary figures of support were strongly devoted to take care of the mother during the acute psychotic episode. Seven mothers explained that they had turned to their family of origin to receive care during psychotic breakdowns, even if they were not living with them. Supporters also explained how during acute episodes of illness they had received the mother in their house or went to live with her to her house.

> *'I had a paranoid crisis, I was terrible, but I was not hospitalized, I stayed with my mother' (Quote 1:128, Mother with SMI, Granada)*

Mothers and supporters in Granada explained that additionally, supporters had to take full care of children while the mother received treatment and recovered from the relapse, since most mothers were not capable. The most common scenario, as referred by five mothers in Granada, was that mothers were cared by the main figure of support, recurring to secondary sources of support to take care for their children. Sometimes caring for the child during these periods was restricted to supply food or cover economic needs.

> *'My mother was the one that supported me a lot, also my sister. My sister was coming here to give him a bath and dress him… during four months… she was feeding him the bottle' (Quote 6:34, Mother with SMI, Granada)*

Mothers and supporters in both places mentioned other tasks of supporters that they considered important during relapses, included noticing symptoms of relapse, taking the

mother to the doctor or the nurse of the mental health team or decide hospitalization. Several participants in both regions, explained that secondary figures of support had been the ones intervening to look for professional support. Some participants also talked about the emotional support given by supporters to the mother, through visits or company. Some participants additionally talked about how supporters had to take care of the house during the mother's relapse.

> *'My brother noticed something was wrong and took me to the doctor… I got upset but now I am grateful… and then he told the doctor that I was acting strange.' (Quote 13:16, Mother with SMI, Granada)*

Table 24
Activities of support during psychotic relapses. All participants

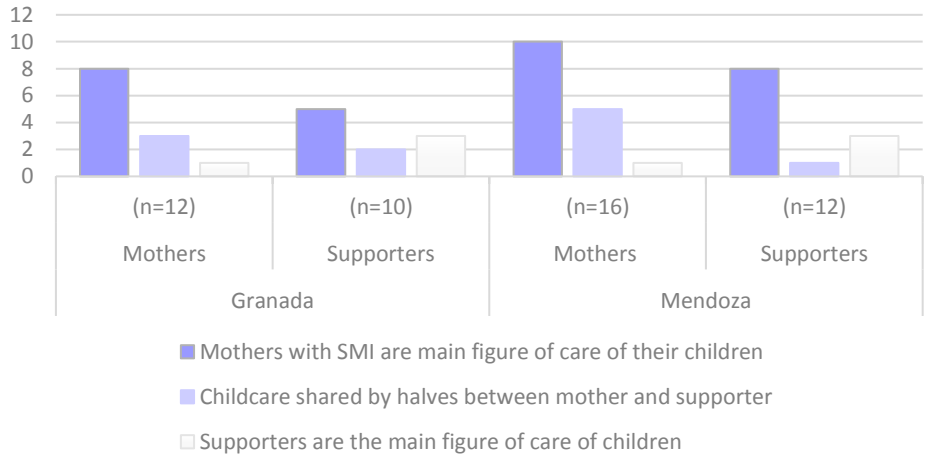
	Granada		Mendoza	
	Mothers (n=12)	Supporters (n=10)	Mothers (n=16)	Supporters (n=12)
Take care of the child while mother was hospitalized	5	5	8	6
Take care of the child even when the mother was not hospitalized, or after hospitalization	11	9	15	12
Take care of the mother at home	7	5	5	5
Others:				
Noticing symptoms of relapse and get professional help	6	4	1	2
Decide hospitalization	-	-	-	3
Emotional support	1	2	2	-
Household	4	1	1	1

4.3.2.2. Activities of supporters during moments of stability

During moments of stability of the mental illness, most ***mothers*** in both sites of study considered themselves to be the ***main figure of care of their children*** and counted with supporters to occasionally or regularly intervene in childcare and education (See Figure 8). In accordance with the account of mothers, in both places most supporters considered mothers to be the main figure of parenting of their children, while their aid was seen as a complement which would not replace the mother in her functions. Less frequently, the mother did not consider herself as the main carer of her children, but permanently ***shared childcare by halves with the supporter***. Some figures of support coincided with the

account of mothers in this sense, but others considered themselves to be fully responsible for childcare and education. This type of involvement where ***informal carers were the main figure of care and education of children*****,** was admitted with more frequency by supporters than by mothers, and occurred in five cases in a permanent way, lasting to the day of the interview. Only in two cases, one in each site of study, the mother openly talked about the supporter taking over most childcare tasks and herself having little responsibilities with her child. In all cases but one, it was the mother of the mother with SMI who took this role. The exception was a participant in Mendoza who was the eldest daughter.

Figure 8
Main figure of care of chidren. All participants



Regarding the type of activities performed by supporters during moments of stability, mothers extensively talked about different types of aid and support in parenting. Two main categories emerged, namely ***activities and functions directly related to parenting and childcare***, and ***activities and functions indirectly related to parenting***, which includes support in other areas of mother's lives that still has an indirect influence on their mothering role. Several themes were identified in each of these categories and will be explained in the following paragraphs according to the view of mothers and supporters in both sites of study, highlighting the differences in groups when they were relevant. Figures of support in both places had slight differences with mothers in the ways they considered their functions. While mothers talked about supporters influencing their roles as mothers in direct and indirect ways, supporters tended to consider their role in childcare and

education as more fundamental. They also talked about other activities of support in more detailed and complex way than mothers.

a. Activities of support directly related to parenting and childcare

Mothers and supporters in both sites coincided in their accounts in considering four main ways of directly intervening in parenting, which did not exclude one another. Themes identified in this respect are summarized in Table 25, and included: a) ***direct performance of tasks with children***; b) ***mediation of interactions between the mother and child***; c) ***provision of adequate material conditions for childcare***; and d) ***being attentive to children's needs***.

Table 25

Activities and functions of supporters directly related to parenting. All participants

	Granada		Mendoza	
	Mothers (n=12)	Supporters (n=10)	Mothers (n=16)	Supporters (n=12)
Direct intervention in childcare	10	9	12	8
Mediation of mother-child interactions	9	8	11	9
Provision of adequate material conditions for childcare	8	7	11	8
Being attentive to child's needs	3	5	4	5

- ***Direct performance of childcare tasks***

As can be seen in Table 26, almost all participants in all groups talked about supporters being directly involved in child raising and care, mainly through performing instrumental tasks and educating children. Other childcare activities were mentioned with less frequency, including taking full care of the child during brief periods of time or fulfilling the role of an absent father.

Regularly or occasionally assuming ***instrumental childcare tasks*** was mentioned by most participants as one of the most important functions of supporters. Many activities were performed in this sense, including preparing food, feeding and watching for adequate nurturing, watching for children's hygiene, waking children up, dressing them, taking them to school or to social activities, and helping them with homework. Some supporters in Granada additionally mentioned to be responsible for child's health. Talking, playing and doing activities with child was highlighted by one supporter in Granada as an important function that had an impact on child's education.

'She gives up, and I would give up too, but no, because the child is there and you have to wake up every day at eight to prepare him breakfast, prepare his clothes, check that his homework is done… and talk to him, because she does not talk much with him.' (Quote 12:80, Supporter, Granada)

The other most frequent activity of support in this sense, according to around 50% of mothers and supporters in both sites, was to engage in ***child education and setting limits***. They mentioned several activities they performed that were related to education, as watching for children's behavior, educating them, setting limits, being the main figure of authority and giving them a sense of security.

'My siblings, it is like if they were their parents. They put limits to them, tell them what they can do and not. They are like other parents for my children' (Quote 26:45, Mother with SMI, Mendoza)

Following, several mothers in both places and some supporters in Granada explained that supporters regularly or occasionally ***took full care of children during periods of time*** *of few hours or days*. In general, this responded to the need of the mother to have some time to rest or to be able to do other activities like going to the doctor or working, while she was habitually who assumed childcare.

'If I ask my sisters to take care of my son, they will, without any problem. Even some weekends one of them takes him with her, so I can rest…' (Quote 44:9, Mother with SMI, Mendoza)

Additionally, some supporters in Granada considered themselves or other carers to be fulfilling the paternal role, in cases when the father was absent.

'*His uncle, the one that is single, he dedicates a lot of time to the child. It is a bit like if he is substituting the image of the father' (Quote 12:159, Supporter, Mendoza)*

Table 26
Activities and functions of supporters directly related to parenting: Direct intervention in childcare. All participants

	Granada		Mendoza	
	Mothers (n=12)	Supporters (n=10)	Mothers (n=16)	Supporters (n=12)
Instrumental childcare tasks	**7**	**7**	**7**	**5**
Child education and setting limits	6	4	9	6
Take care of children when the mother can't	**5**	**3**	**9**	**5**
Paternal role	-	3	-	-

- ***Mediation of mother-child interactions***

Most participants talked about supporters acting as mediators of mother-child interactions and mother's activities with children. Mediation could be practiced by giving the mother ***advice, guide and orientation regarding diverse aspects of childcare and education***, including how to perform instrumental tasks, set limits to children, organize activities and solve problems (See Table 27).

> *'Many times, she comes and asks me, my child said this and that… how do you see it? And well, I tell her my opinion.' (Quote 23:30, supporter, Granada)*

Sometimes advice pointed to make the mother aware of some behaviors the supporter considered inappropriate, like yelling, using physical violence, overprotecting, exposing the child to risks, or treating children in unequal ways.

> *'J. would hear me shouting to her and he would tell me that he didn't like it, and not to do it again…' (Quote 18:37, mother with SMI, Granada)*

Additionally, supporters in both places, but not mothers, talked about different ways in which they tried to ***stimulate the interaction between the mother and child***, and tried to involve her in childcare tasks (See Table 27). One of the caregivers explained that he gave special attention to only intervene when he saw the mother was having difficulties, so that in the rest of cases her confidence and independence was strengthened.

> *'She has to have aid, like a basis. But from there you must leave her alone… It is like a game, to be with her without being. To be attentive so there are no mistakes, but also that she does not notice that you are telling her to put him the diaper, or so…' (Quote 15:54, supporter, Granada)*

Table 27

Activities and functions of supporters directly related to parenting: mediation of mother-child interactions. All participants

	Granada		Mendoza	
	Mothers (n=12)	Supporters (n=10)	Mothers (n=16)	Supporters (n=12)
Advice, guide, orientation regarding childcare	9	7	11	8
Stimulation of mother-child interaction	-	3	-	3

- ***Provision of adequate material conditions for childcare***

As was mentioned in the socio-demographic characteristics, most mothers with severe mental illness lacked economic independency, even when they received a disability

pension. So, in both sites of study, primary figures of support were generally in charge of ***fully or partially covering the economic needs of mothers and children***. While this aid was acknowledged by most participants in both sites of study, some did not count this as a function of support but seemed to be a natural function of partners and families of origin.

As can be observed in Table 28, only some primary figures of support stressed the fact that their support was, among others, economic. Only two figures of support -one in each country- talked about this type of support as burdensome. Many of them did highlight and highly valued the economic support given by other people to the mother and child, in regular basis (especially by the father of children when separated from the mother), or occasionally (by family members, and in one case by neighbors).

Mothers also explained that economic support could be received on a regular basis, through the payment of services or food, through the full economic maintenance of the mother and her child, or through the direct provision of money every month. Other mothers talked about supporters occasionally providing economic aid when they had a special need or when the supporter had an extra income.

> *'My mother… she takes care economically of my child… he lacks no food, no clothes… he has all the love in the world, has toys, a computer… he has everything!' (Quote 11:91, Mother with SMI, Granada)*

Additionally, guaranteeing adequate material conditions for the mother and child included providing ***housing and a calm and safe environment*** for them. One mother in Granada explained:

> '*In my house, with the simple fact of living there, she is out of there of that complicated ambient…' (Quote 16:100, supporter, Granada)*

Table 28

Activities and functions of supporters directly related to parenting: provision of adequate material conditions for childcare. All participants

	Granada		Mendoza	
	Mothers (n=12)	Supporters (n=10)	Mothers (n=16)	Supporters (n=12)
Economic aid	7	6	10	7
- ***Full economic maintenance of mother and child***	*3*	*4*	*3*	*4*
- ***Regular payment of services or food***	*1*	*-*	*3*	*-*
- ***Regular provision of money***	*1*	*-*	*2*	*2*
- ***Occasional economic aid***	*2*	*2*	*3*	*3*
Housing, safe and calm environment	2	3	4	-

- ***Being attentive to the mother and the child***:

Finally, as was seen in Table 25, some mothers and supporters in both places talked about supporters being constantly attentive to the child and the mother, so to be able to provide help when needed or cover any need they observed.

> *'They have always been very attentive, and even more since I became ill… They always ask me… and come to talk to the doctor, to check if I am fine or if I need something' (Quote 26:29, mother with SMI, Mendoza)*

b. Activities and functions of support that indirectly influence parenting and childcare

When talking about support to mothers in their parenting role, participants identified activities of support in several areas of mothers' lives which indirectly affected their parenting. Seven main themes were identified regarding support that indirectly influenced parenting, which are summarized in Table 29, and explained in the following paragraphs.

Table 29
Activities of support indirectly related to parenting. All participants

	Granada		Mendoza	
	Mothers (n=12)	Supporters (n=10)	Mothers (n=16)	Supporters (n=12)
Reaffirmation and emotional support	7	8	5	9
Maintain health and stability of the mother	4	8	8	4
Motivation and keeping activity	2	6	5	2
Aid in domestic activities	4	5	3	1
Socialization	5	4	3	2
Being attentive to the mother	3	6	-	2
Others:				
- ***Foresee problems in the future***	-	*3*	-	*3*
- ***Promote autonomy of the mother***	-	*2*	-	-
- ***Social dimension of care***	-	*2*	-	-

- ***Reaffirmation and emotional support***

Most participants in both places thoroughly talked about different ways of giving and receiving emotional support. As can be seen in Table 30, the most frequent way of providing emotional support overall, and especially in Mendoza, was through *company and sharing activities with the mother*.

'My mum used to come every day, and my dad too. I have had much family support, my parents, my brothers, they were coming to see me… my nephews… they never left me alone, never.' (quote 51:14, Mother with SMI, Mendoza)

Mothers in Mendoza also frequently talked about supporters giving them a *feeling of security*, making them feel sure they would always be present for her and her children and having a general supportive attitude.

'I can always count with my parents to be next to me.' (Quote 51:42, Mother with SMI, Mendoza)

In Granada, the most common way of providing emotional support mentioned by mothers was being able *talk about their experiences, feelings and concerns with their caregivers*. Some mothers specifically mentioned that supporters helped them to deal with their feelings related to motherhood.

'To have someone to listen to me is always good… now it is my husband, he is the one that is there and listens to me… only him.' (Quote 1:77, Mother with SMI, Granada)

Additionally, supporters mentioned *giving love and affection* to the mother as a very important function, especially in Granada. Some also talked about their efforts to cheer the mother up.

Table 30

Activities of support indirectly related to parenting: Reaffirmation and emotional support. All participants

	Granada		Mendoza	
	Mothers (n=12)	Supporters (n=10)	Mothers (n=16)	Supporters (n=12)
Company and sharing activities	5	3	7	4
Feeling of security, general supportive attitude	3	4	7	1
Talks and advice about experiences, feelings and concerns	8	1	2	-
Love and affection	-	4	-	2
Cheer the mother up	1	1	1	-

- ***Maintain health and stability of the mother***

Another very frequent function of supporters was to try to maintain the mother healthy and stable, as shown in Table 31. Most participants of all groups talked about supporters involving themselves in the *control and treatment of mental illness*. In this respect, many controlled the evolution of illness by watching behaviors of the mother, and when

symptoms of relapse were noticed they took action by taking the mother to receive professional care. Most supporters also controlled the intake of medication in a daily basis and accompanied the mother to the consultations with the psychiatrist in a regular way.

> *'My brothers have me under control. As soon as they see something wrong they will tell me and take me to the doctor.' (Quote 13:75, mother with SMI, Granada)*

Supporters talked about other activities they performed in order to prevent relapses, that mothers did not mention. Some explained they frequently talked with mothers and advised them about behaviors they considered inappropriate. Additionally, supporters in Granada mentioned they tried to avoid situations of distress from mothers and suggested psychological treatment for mother and child.

> *'I tell her she cannot work so much, she needs to rest more, sleep more hours. And if she can't then she should not do it, we will help her somehow but she cannot make herself become ill.' (Quote 24:73, supporter, Granada)*

Informal carers were also involved in other areas of health care. In Granada participants mentioned supporters watching for the mother's healthy habits, and in one case helping in dressing and bathing of a mother who lacked autonomy in some activities of daily life.

> *'She spends 5-6 hours sitting in the chair, and she is gaining weight… I tell her to go out and take a walk, she cannot be in the house without moving for so many hours! She needs to move, it is good for the body' (Quote 23:44, supporter, Granada)*

In Mendoza, it was common that supporters helped the mother to manage health care and insurance resources as well as dealing with paperwork related to disability pension. Finally, participants in both places mentioned that some supporters were involved in reproductive decisions of mothers.

Table 31

Activities of support indirectly related to parenting: Maintain health and stability of the mother. All participants

	Granada		Mendoza	
	Mothers (n=12)	Supporters (n=10)	Mothers (n=16)	Supporters (n=12)
Control and treatment of mental illness	6	6	7	5
Healthy habits	2	2	-	-
Reproductive decisions	2	1	1	-
Manage health care, insurance and pension resources	-	-	4	3
Assistance in activities of daily life	1	1	-	-

- ***Motivate and keep the mother active***

As was shown in Table 29, some participants, especially supporters in Granada and mothers in Mendoza, talked about supporters keeping the mother active and motivated during the day. They tried to make mothers go out go out or get engaged in different type of house or working activities. Some also helped her to organize daily routines and activities. *'Keep her busy'* was explained by some caregivers as a way of preventing the mother with SMI to get worried about her delusional ideas, finally serving as a way of avoiding distress.

> *'You have to always keep her busy. We have to do this, to do that, we will clean here, go there, take a walk… so that she will not be thinking about any problem… because she makes a world out of any problem' (Quote 15:22, Supporter, Granada)*

- ***Aid in domestic activities***

As shown in Table 29, some mothers and supporters, especially in Granada but also in Mendoza, considered aid in domestic activities as an activity of supporters. Most of them considered that relieving the mother from some of her tasks and burdens could allow her to feel more energy or have more time to spend with her children.

> *'I had to pay attention to the child, be attentive to each little thing! That's why my mother was cooking and ironing, because I had to be attentive to the diapers, the milk… the time schedule of the babies…' (Quote 45:49, Mother with SMI, Mendoza)*

- ***Promote socialization of the mother***

Some participants, especially in Granada, talked about supporters helping the mother in social insertion in different ways (See Table 32). Frequently supporters tried to take the mother out or stimulate them to go out. Some mothers highlighted the possibility this gave to their children to see other people and play with other children. Additionally, a few mothers talked about the importance of being assisted in transportation, which made it easier for them to go out. Some mothers in Granada also talked about places and environments that made them feel good, as the gym '*a place to make social contacts, relax, feel well*' (Quote 1:39, mother with SMI, Granada), and the hairdresser, a place where she could '*meet others, make them laugh, laugh and relax*' (Quote 3:75, mother with SMI, Granada).

'She does not want to go to the workshops… And I tell her she should go, in this way at least she would go out and relate to other people, not be in her room all day…' (Quote 12:79, supporter, Granada)

Some supporters considered other ways to promote social insertion of the mother. They talked about helping them to find a job, to manage money, and offering mothers to take care of the child so they could develop some social and working activities.

'We always tell her to leave her child here with us during the weekends and holidays, so she can go out and do not worry about them' (Quote 16:38, supporter, Granada)

With a different perspective, in both places some supporters restricted some type of social interaction of mothers. The main restriction of socialization was with groups that were considered risky because of the use of drugs. In Granada one mother described her supporters hindering her from making and meeting friends, given their fear of her getting pregnant again.

'I cannot leave her with the keys of the house for her to leave, because I don't know where she can go and if she will come back… She is very sociable and any person can convince her… to steal the baby, or do something to her…' (Quote 42:59, supporter, Mendoza)

Table 32

Activities of support indirectly related to parenting: Social insertion. All participants

	Granada		Mendoza	
	Mothers (n=12)	Supporters (n=10)	Mothers (n=16)	Supporters (n=12)
Go out	3	2	3	2
Supportive environments	2	1	-	-
Find a job, manage money	1	2	1	1
Restriction of social contacts	2	2	3	4

- ***Being attentive to the mother***

Many supporters, especially in Granada (See Table 29), considered that one of their functions was to be attentive to the mother, so to cover any need that arises. Some considered their functions in a total and broad way, doing all for the mother and giving her complete physical, mental and economic support. Others restricted their role to cover basic needs and wellbeing of mother.

'*Me, my husband, and my daughter… we are all helping. She has much support, we are all attentive to her and her children' (Quote 7:5, Supporter, Granada)*

- ***Other functions and activities of supporters***

As show in Table 29, some participants mentioned additional activities of support with less frequency. Supporters in both places talked about trying to ***foresee problems the mother would have in the future*** when they would not be present, and, in advance, prepare the mother to overcome them. Some strategies for this included to maintain contact of the mother with her siblings so that they would care for the in the future, prepare the child to care for the mother in the future, guarantee economic wellbeing of mother and children for the future, prepare a calm family context for mother in the future.

> *'I always tell her she needs to learn how to save money, she will need it for her life… I always remind her that I am a person of advanced age and will not be always here… and she will not know how to do anything…' (Quote 50:9, supporter, Mendoza)*

Additionally, in Granada, some supporters stressed their function as ***promoters of the autonomy of the mother***, by respecting and stimulating her actions and decisions.

> *'When she got pregnant I told her that I would not tell her what to do… she was responsible for the decision. I would tell her, but I could not… so she made an appointment and had an abortion' (Quote 12:280)*

Some supporters in Granada also stressed a **social dimension** of their functions as carers. One directly was occupied in giving advice, motivation and example for other people in similar situations, others expressed their interest in participating in the research to help others in similar situations, and one expressed her effort in raising a child that would be respectful of society and environment, while taking care of a problem that society cannot take care of.

4.3.3. STRATEGIES OF SUPPORT

The supporting activities performed by caregivers were not always easy to implement. Many explained how they had to make sure that the aid they were offering would be accepted by the mother, while many times they were worried about not making her dependent on aid or cause any other problems. As well, mothers struggled with the fact of

needing support but not knowing how to ask for it, or not always liking the way it was being provided.

In both places, many mothers talked about strategies they used to receive or to deal with support so that it turned out to be satisfactory (See Table 33). Some strategies were ***passive***, like waiting for family members to notice their needs and offer help; accept the support the way it was given bearing up with aspects they don't like; accepting the final word and rules of supporters in case of disagreements; or avoiding conflicts by not talking. Passive strategies were mentioned with a higher frequency in Mendoza than in Granada, as can be observed in Table 33.

> *'I would not like to ask them more than what they are already doing, it could be disturbing for them. Because I think that for an ill person… the other person that is healthy must notice by herself that you need help' (Quote 44:70, Mother with SMI, Mendoza)*

More frequently mothers recurred to ***active strategies***, as mentioned by all mothers in Granada and most mothers in Mendoza. In Granada, mothers especially talked about actively ***requesting the type of aid they needed***, like company, ask for someone to take care of child during moments they felt bad or when they needed to go out, economic aid, advice and orientation about childcare and solving problems of daily life. One mother highlighted the fact that she preferred to ask for support when needed than having someone caring all the time.

> *'Whenever I see myself overwhelmed, that I cannot do it anymore, I go to my mother's house' (Quote 1:83, Mother with SMI, Granada)*

Very frequently mothers in both sites of study talked about ways in which they got involved in care so to become more than a receiver of care. They talked about trying to ***participate in support***, mainly by being involved in the tasks of caregivers. Other ways to be involved were reminding the supporter of their activities, propose alternatives to feel well with received care, coordinating activities between all supporters and herself and making economic contributions for house expenditures.

> *'We organized all tasks and I am participating more in my child's education… give him a bath, prepare him food, help him with homework.' (Quote 11:95, Mother with SMI, Granada)*

Others talked about accepting support as a *share of activities* related to childcare and house tasks with the supporter.

> *'I feel a big complicity with my parents, because we share education by halves. Fifty percent, as in a marriage… but in the relationship between grandparents and children' (Quote 25:48, Mother with SMI, Granada)*

Many participants, with higher frequency in Mendoza than in Granada, sought to ***reciprocate support*** and make a more equal distribution of efforts among them and their caregivers. In this way, many mothers felt better with the aid they received and felt active and autonomous. *Reciprocity* was sought by offering mutual support and help to their family members through giving affection, doing domestic tasks, collaborating in house expenses or making an economic retribution to the supporter. Less frequent ways of giving reciprocal aid were taking care of supporter's children, taking care of family members in need, giving housing to the supporter and helping in commercial activities.

> *'We have to help each other. When they need, it we are there, and when I need it they are here… it is mutual… we all help each other' (Quote 43:75, Mother with SMI, Mendoza)*

Less frequent, and especially in Mendoza, some mothers tried to ***reduce conflicts in the relationship with their caregivers*** by gaining independence and autonomy from them, or by suggesting psychological aid for the supporter. As well, only in Mendoza, some talked about trying to protect the supporter from becoming overwhelmed.

> *Every day I tell him, when we go to the grandmother's house, that he should do things that he likes! He could ride the bike, relax a bit…' (Quote 39:72, Mother with SMI, Mendoza)*

Table 33

Strategies of support. Mothers, both sites of study

	Granada (n=12)	Mendoza (n=16)
Passive strategies	2	6
Ask for needed help	7	4
Participate in support	5	5
Reciprocate support	6	12
Reduce conflicts with supporter	1	5

Caregivers also talked about different strategies they used to provide support in parenting to the mother with SMI (See Table 34). Like mothers, half of supporters in both places talked about ***strategies to involve the mother in support and make her actively participate*** *in several activities*, including her own care, childcare and household tasks.

> *'When I see that she can do something, then I let her do it. I don't say anything, I don't do it myself, no… I can see she is doing well and let her try…' (Quote 48:32, supporter, Granada)*

Half of supporters also talked about how they tried to ***respect and promote autonomous decisions and actions of mothers*** in areas related to her personal life and personal care. Some took especial care of *respecting and stimulating the mother's role and hierarchy*, and not making her feel excluded from the care of the child. This could be achieved by requesting a shared custody of the child, verbalizing the importance of the mother in childcare or controlling but letting her do tasks by herself. Less frequently, supporters tried to make their interventions less noticeable, for example intervening only when the mother was not present.

> *'I would not leave her aside and put myself in the front, no… His mother is his mother, and the grandmother is the grandmother, a more secondary thing…' (Quote 23:29, supporter, Granada)*

Less frequent, caregivers tried to involve mothers in ***reciprocal care***, so that the mother with SMI would collaborate in household tasks, care for an ill relative, or contribute economically to family expenses.

> *'Helping her is beneficial for me too because I help her and she helps me to take care of my husband. Otherwise I don't know how I would do, because we cannot leave him alone at home' (Quote 31:40, Supporter, Mendoza)*

To respect the mother's positions and decisions and be able to provide more adequate care, some supporters considered it important to ***understand her better and*** with that aim many looked for information about mental illness or tried to listen to the mother's thoughts.

> *'I have learned to listen to her, to wait, not to insist. And while we are talking I explain her and she accepts… that's why I think it's a matter of understanding her' (Quote 34:21, supporter, Mendoza)*

On the contrary, some supporters- only in Mendoza- talked about the use of ***strategies that could hinder the autonomy of mother***, like hiding information from her, taking

decisions about her personal relationships, not leaving her alone and sometimes locking her in the house with the child.

Table 34
Strategies of support. Supporters, both sites of study

	Granada (n=10)	Mendoza (n=12)
Involve the mother to be active in support	5	6
Respect and promote autonomy of the mother	5	6
Involve the mother in reciprocal care	1	4
Understand the mother better	4	4
Restrictive strategies	-	4

4.3.4. SATISFACTION AND VALUATION OF SUPPORT

While most participants talked about diverse problems and difficulties that appeared during the process of caregiving, many also talked about positive aspects and satisfaction with care. As shown in Table 35, most mothers in both sites of study were happy and highly valued the support they received, especially because of its ***loving quality***. In this respect, mothers talked about the emotional containment and security they felt coming from their caregivers, and about the effort, love and generosity supporters put in helping them. Many highly valued the ***good relationship existing between mothers and their figures of support*** as well as its' ***positive impact on their own and on children's wellbeing***, their contact with the world and even their survival.

> *'If it would not be for my partner, none of us… I would be hospitalized somewhere, crazy or dead. And my daughter would be with other people, or lost… (Quote 39:115, Mother with SMI, Mendoza)*

In more moderate terms and with higher frequency in Mendoza, some mothers expressed a ***partial satisfaction*** with received support, valuing specific aspects of it like childcare, housing or economic aid.

Table 35
Satisfaction with support: Positive valuation. Mothers, both sites of study

	Granada (n=12)	Mendoza (n=16)
Good relationship between mother and supporter	6	12
Positive impact on mothers' and children's wellbeing	7	9
Loving quality of support	4	7
Partial satisfaction	1	7

Caregivers tended to value their experience of support in more negative terms than mothers. Still, they highlighted several positive aspects, as can be observed in Table 36. They especially highlighted their ***relationship with children***. Taking care of children was considered a very pleasant experience in which they got very much involved. Many supporters thought of children as their own and considered them to be a source of joy, strength and value in life. Other positive aspects of care where related to ***satisfaction with the aid they could provide***, since they felt they were accomplishing an important role and could properly deal with the situation.

> *'I learned to value life more. This experience taught me to value life more, much more… before I was all about work, I made my money but… now it's all about my wife and my son.' (Quote 15:58, supporter, Granada)*

Satisfaction was also expressed by caregivers regarding the ***good relationship established between mother and supporters***, or about ***not having disagreements with her.*** Others highlighted the ***good relationship existing among family members and other figures of support***, and many expressed gratitude for the support they received from their close social network. Finally, some tended to ***normalize the situation of support and problems that arose during it,*** considering them as normal situations in life and partnerships. This tendency was higher in Mendoza, expressed by one fourth of supporters compared to only one tenth in Granada.

> *'I am taking it naturally, because I think that if some problems don't have an immediate solution you have to accept it, and well, find the way…' (Quote 42:69, supporter, Mendoza).*

Table 36

Experiences of support: Positive aspects. Supporters, both sites of study

	Granada (n=10)	Mendoza (n=12)
Positive aspects associated to children	8	5
Satisfaction with the aid they give	5	5
Good relationship with the mother	4	5
No disagreements with mother	2	3
Good relationship among supporters and family members	4	4
Satisfaction with support from others	3	5
Normalization	1	3

4.3.5. PROBLEMS WITH SUPPORT

Several participants in both sites of study made some negative valuations of the received support, in relation to several problems that appeared during the process of giving or receiving aid. In the account of mothers, it was possible to identify seven themes related to these issues, presented in Table 37. Caregivers identified similar problems than mothers in both sites of study, but mentioned additional themes which were the most frequent problems for them. These themes were almost absent in the accounts of mothers, and included the consequences of care on their lives, including emotional, social and physical consequences. In Table 39 these are resumed under the category '*Supporters are affected by their role'*, which will be explained in more detail in the following lines.

It was noticeable that some participants in Argentina, most of them mothers, did not talk about ***any specific problem*** in the process of support.

Table 37

Problems with support. All participants

	Granada		Mendoza	
	Mothers (n=12)	Supporters (n=10)	Mothers (n=16)	Supporters (n=12)
Difficult mother-supporter interactions	9	7	11	6
Isolation and difficult interaction with other family members	4	7	1	7
Disagreements	3	3	9	4
Displacement of the mother in her role	5	3	5	5
Support as double-edge sword	3	3	4	3
Worries about the future	2	4	3	7
Insufficient support	2	-	9	-
Supporters are affected by their role	-	9	1	10
No specific problems	-	-	5	2

The themes identified in the accounts of mothers and caregivers will be exposed in the following paragraphs, highlighting the differences that appeared among groups:

- ***Difficulties in the interaction between mothers and supporter****s*

Several participants talked about conflictive interactions between the mothers and their figures of support, which included frequent discussions and confrontations, problems in communication and negative feelings and attitudes towards each other (See Table 38).

Many mothers in both places talked about having a **bad relationship** with supporters, frequently engaging in **discussions and quarrels** which could reach the point of verbal or physical aggressions. In Mendoza, two mothers talked about episodes where the intervention of police was needed to stop the confrontation.

> *'I don't speak with my mother anymore, it's like a boredom… we almost don't talk. We talk a little and sometimes when we walk together she starts to say I am too weak, and I start to tell her she is a witch… and we start insulting each other…' (quote 3:77, mother with SMI, Granada)*

Tensions were so strong, that some mothers considered these ***invalidated all received aid***.

> *'She helps, she helps me and all, but there are moments when I get angry, she makes me so nervous that I think, my God, what is her help worth for!' (Quote 1:98, Mother with SMI, Granada)*

Coinciding with the accounts of mothers, several supporters talked about ***having a bad relationship, frequent discussions and conflicts with the mother***. A few talked about occasions in which mothers had extreme reactions like becoming physically aggressive with the supporter or with objects, calling the police to accuse them of maltreatment or child abuse. With sadness, some supporters admitted that mother's aggressive reactions restricted the amount and type of support she received.

> *''The problem was so big that… sometimes I could not be next to her, she did not allow me to care for the children, because I would have done more' (Quote 46:103, supporter, Mendoza)*

On the other hand, mothers in both places expressed **negative feelings about supporters**, including *mistrust* and *irritability*. Mothers described mistrust and uneasiness when supporters took care of their child, since they suspected they would want to keep the child, take advantage of, or hurt their children. Others felt irritated by supporters, just because of their presence or because of personal characteristics that they found hard to deal with, like anxiety, irritability, aggressiveness, distant and hard character, or on the contrary a passive and soft character.

> *'She is annoying. Annoying! She tells me to make my child silent, make her shut up! But the way she reacts… its' not the way' (Quote 32:34, Mother with SMI, Mendoza)*

It was common that *supporters* were *perceived* by mothers *as over-protective, too attentive, possessive, controlling, intrusive or as interfering* in all areas of the mother's life. Others perceived supporters as *bossy and arbitrary*, while others complained about feeling treated as a child.

> *'I get irritated by his parents… not because they are bad, no, it is just that they interfere a lot in our family… some things they should better ask. Ask if we need something instead of taking it for granted. That's why I sometimes say that they interfere too much in my life, in our life… and it can be uncomfortable' (Quote 18:111, Mother with SMI, Granada)*

Many supporters observed that mothers frequently got angry with them and did not like or accept the support that was being offered, especially regarding child care and education. Some thought that mothers tended to reject aid when it was felt too invasive or forced. Other caregivers tended to explain a bad relationship as caused by mistrust and rejection from the mother, that sometimes blamed them for their problems.

> *'In front of her I cannot say anything to her daughter. I cannot discipline her, or tell her, or lecture her, because the mother gets upset with me. And I am only trying to help her daughter!' (Quote 46:88, supporter, Mendoza)*

Mothers also felt inappropriate attitudes from supporters towards them, which included **getting upset, rejecting or criticizing them, sometimes demanding too much.** Many felt threatened by supporters, who menaced to take the child away from them. In a few cases, some supporters did try to do it, according to the mother's accounts. Some supporters admitted becoming angry because of different attitudes of the mother with SMI, especially passive attitudes and scarce daily activity. Others expressed difficulties in the interaction with children directly, getting irritated by some of their attitudes and behaviors.

> *'Sometimes if I say something… if I am speaking, with no bad intention, then my sister starts accusing me. She tells me that if I remain like this I will get an injection and my child will be taken away from me…' (Quote 33:61, mother with SMI, Mendoza)*

Additionally, mothers talked about feeling stigmatizing attitudes from supporters towards them. Some noticed that they did not take their opinions into account because of their mental illness, or that supporters and people in general avoided talking about the mental illness

"I have the feeling that because of having an illness, sometimes everything I say is... nonsense, people take it as nonsense' (11:123)

Several mothers considered that a lack of information and understanding of mental illness made supporters treat them inappropriately. In this respect, several supporters, mainly in Mendoza, expressed difficulties to understand the mother and her illness, especially when they affected her parenting abilities. Similarly, in Granada it was common that supporters felt they lacked information and were not prepared to deal with the situation of supporting a mother with severe mental illness.

'I don't understand the illness she has. And I don't understand her either, because many times I think she should make an effort. If she does not help herself, we cannot do much… more than cooking and taking care of her… but she has to do an effort, but no, she just locks herself up' (Quote 38:10, supporter, Mendoza)

Finally, a common difficulty in the interaction expressed by mothers but absent in the accounts of caregivers were **problems in communication**. Some mothers experienced general problems in establishing dialogue with figures of support, difficulties to express discomfort and disagreements with supporters, to request help or to talk about intimate concerns. Mothers also mentioned misunderstandings and communication problems supporters had with them, since they did not talk about some important home issues, or were not direct requesting what they wanted.

'I do not count on my mother to be listened to… no, I don't tell her anything… with her I am closed, totally closed' (Quote 1:76, Mother with SMI, Granada)

Table 38

Problems with support: Difficult mother-supporter interactions. All participants

	Granada		Mendoza	
	Mothers (n=12)	*Supporters (n=10)*	*Mothers (n=16)*	*Supporters (n=12)*
Bad relationship between mother and supporter:				
- ***Discussions and quarrels***	5	3	8	3
- ***Verbal or physical aggressions***	2	-	2	3
Negative feelings and attitudes from mothers towards supporters:				
- ***Mistrust and irritability***	3	6	5	6
- ***Supporters are perceived as controlling and excessive***	4	1	6	2
- ***Mothers reject support***	-	4	-	5

Inappropriate attitudes from supporters towards mothers:				
- ***Irritability, anger, criticism, over-demanding***	4	3	7	4
- ***Stigmatizing attitudes***	2	-	2	-
- ***Supporters lack understanding of mental illness and mothers' experiences***	3	5	4	4
Problems in communication	6	-	5	5

- ***Isolation and difficult relationship among caregivers***

Several supporters in both places expressed to have a ***tense relationship with other supporters***, having ***disagreements*** about how to provide support or feeling other supporters were not being responsible enough. Many also ***felt criticized on how they provided care***, and complained about feeling ***lonely, isolated and lacking aid*** of other family members (See Table 39).

> *'There is always like a critical atmosphere… like if you never do things right… about what should be done. Why do you do this, why do you do that… then you start to take distance, you start to isolate yourself… The result, at least for me, is that I am getting more and more isolated from others, from the rest of my family.' (Quote 12:44, supporter, Granada)*

As seen in Table 39, some caregivers understood that relatives distanced from the mother and the supporter because they felt tired of permanent tension and conflicts, or because they had difficulties to interact with her. Many also thought that relatives and friends took distance because of stigma related to the mental illness, or because they did not understand the mother and the symptoms of illness. On the contrary, others held the mother responsible for the isolation, explaining that her constant feelings of jealousy prevented the supporter to relate to others and conform a network of support.

> *'My family does not know about her illness… because she has been rejected so much before… her friends, as soon as she told them about her illness, they rejected her.' (Quote 9:11, supporter, Granada)*

Some mothers in Granada also talked about conflicts between different family members. They felt different figures of support had conflicts between each other or blamed each

other for child and mother's problems, and some felt the caregiver produced splitting within the family.

> *'My youngest brother could not handle it when I tried to suicide. Since then, we have seen each other less… and my other siblings were there with me, and are upset with him and my father because they are not giving me the support they should…' (Quote 2:133, Mother with SMI, Granada)*

Table 39

Problems with support: Isolation and difficult interaction with other family members. All participants

	Granada		Mendoza	
	Mothers (n=12)	Supporters (n=10)	Mothers (n=16)	Supporters (n=12)
Bad relationship and disagreements with other caregivers	4	5	1	5
Supporters feel criticized	-	2	-	3
Supporters feel isolated and without support:	-	6	-	7
- Relatives distance because of permanent conflicts and tension	-	2	-	3
- Relatives distance because of stigma associated to mental illness	-	4	-	3
- Mother causes isolation	-	3	-	2

- ***Disagreements between mothers and supporters***

Participants of all groups described the appearance of ***disagreements in various areas of childcare and education*** between mothers and supporters, especially regarding ways of setting limits and ways of performing instrumental tasks with children. These were more common among participants in Mendoza than in Granada, and slightly more common among supporters than mothers.

> *'I am very, very permissive with my children. It is two extremes, because he is too strict and me, I am too kind… and there we crash.' (Quote 30:14, Mother with SMI, Mendoza)*

Less frequently and only in Mendoza, ***disagreements*** were described ***regarding other areas where supporters intervened***. Disagreements were mentioned regarding household and economy by both, mothers and supporters in Mendoza. Both groups of participants in Mendoza additionally mentioned disagreements about receiving or not psychiatric treatment.

- ***Displacement of the mother in her role***

About one third of mothers in both places felt displaced by supporters in their role as mothers. As shown in Table 40, this feeling was motivated because of ***others taking over parenting tasks and decisions, spending more time or having a closer connection with the child than mothers themselves***. Some experienced this as a frustrating situation, that made them feel anxious, useless and even afraid of their children being taken away.

> *'They got used to me not being there, at home… they organized themselves, and when I came back they had their organization and I was set aside'. (Quote 11:94, Mother with SMI, Granada)*

Mothers also felt they ***lacked autonomy and decision capacity*** due to supporter's interventions, especially in childcare. Lack of autonomy was also a complaint referred to other areas of life, like health and healthcare, household, administration of money and organization of free time. Some explicitly mentioned that they would prefer to be more independent.

> *'When she is around I feel nullified, but when I am alone with children then I can be myself… I feel annulated because she wants to have a part to play in all… what you want to eat, what you want here, what you want there… and I feel nullified…' (Quote 1:72, mother with SMI, Granada)*

With similar frequency than mothers, supporters acknowledged the feeling of displacement of mothers. Some explained it in terms of the mother with SMI feeling jealous of them taking care of the child. They explained that sometimes these feelings made the mother feel worse, and could even derive in delusional ideas of supporters abusing the child or wanting to steal it from the mother. Other supporters explained the feeling of mothers as caused not by jealousy but by an actual stronger connection of the child with themselves, or by themselves spending more time with the child than with the mother.

> *'She is aware that she is not doing what she should… and it affects her, she feels less… then she sees me that I do what she doesn't, and it adds to her illness…' (Quote 12:83, supporter, Granada)*

Table 40

Problems with support: Displacement of the mother in her role. All participants

	Granada		Mendoza	
	Mothers (n=12)	Supporters (n=10)	Mothers (n=16)	Supporters (n=12)
Supporters perform more parenting tasks, spend more time with children or have a closer connection with children	3	3	5	5
Mothers lack autonomy and decision capacity regarding childcare	3	-	3	-
Lack of autonomy in other areas	2	-	4	-

- **Support as double-edge sword**

Participants of all groups recognized support to be needed and beneficial, but at the same time identified some negative consequences of it (See Table 41). Mothers and supporters, especially in Mendoza, considered that the aid in childcare made the mother ***be less involved and lose responsibilities with their children***. In Granada, many talked about ***support worsening the course of illness, causing the mother to be passive, frustrated, angry or lazy***.

> *'My mother came here and started to command in all… she was interfering with everything. She made me weak…' (Quote 3:20, Mother with SMI, Granada)*

Some participants thought that support could also ***affect children negatively*** by interfering with their independent actions or discipline, since figures of support tended to be over protective or put less limits.

> *'My daughter she was raised as if only I could put rules on her… because my dad was not strict with her, he did not reprehend her… he was not playing the role of father, but of grandfather… And well, that's why now she does not accept that you put limits to her, or rules…' (Quote 30:50, Mother with SMI, Mendoza)*

Table 41

Problems with support: Support as double-edge sword. All participants

	Granada		Mendoza	
	Mothers (n=12)	Supporters (n=10)	Mothers (n=16)	Supporters (n=12)
Mother gets less involved in childcare	1	-	3	2
Worsening evolution of illness	2	1	-	1
Hinders independence of children	1	1	1	-

- **Worries about the future**

Some participants, with more frequency supporters and especially in Mendoza, expressed ***worries about the mother and the child being dependent on them when they would not be present or able to accomplish their role anymore*** (See Table 42).

> *'I'm like her feet and hands… She cannot live without me… She can't'… the day I die I don't know what she will do… But common, maybe she will survive…' (Quote 4:8, supporter, Granada)*

Some mothers and supporters in both places expressed worries about the ***consequences on children*** of present lack of stimulation, lack of social contacts and lack of economic resources.

> *'My granddaughter, she is in a learning period when she needs to know many things, and I am not sure if her mother can… if her mother has all the necessary abilities to teach her… to teach her to start talking and so… The stimulation she needs now, at this age, I don't think it is hundred percent' (Quote 42:55, supporter, Mendoza)*

With a different perspective, one supporter in Mendoza thought the mother could would be able to handle herself well without support, and one in each site of study thought the mother would be properly cared by her ow ***children***, whom they considered to be the ***future carers of their mothers***.

> *'I have taken a decision, I will teach the child to take care of the mother. I want him to administer things for his mother…' (Quote 50:44, supporter, Mendoza)*

Additionally, some ***supporters expressed worries about their own future*** when they would not be able to help the family anymore, wondering who would take care of them or wondering how they would deal with the feelings of overwhelm they had.

Table 42

Problems with support: Worries about the future. All participants

	Granada		Mendoza	
	Mothers (n=12)	Supporters (n=10)	Mothers (n=16)	Supporters (n=12)
Mother and child being dependent in the long term	2	4	1	6
Child as future carer of the mother	-	1	-	1
Worries about consequences on children of present deficiencies in mothering and support	1	-	3	-
Worries about supporter's wellbeing in the future	-	1	1	1

- **Insufficient support**

Some participants complained about lack of support in general, while others thought supporters did not involve enough in childcare and education, had inadequate interactions with children, or considered supporters did not provide enough company, emotional support, economic aid or aid in the house. Some mothers explained lack of support to be caused by stigma related to mental illness. They explained how stigma made others distance from them, but also made themselves withdraw socially because of shame and the fear of discriminating attitudes of others.

> *'I think why do we have to deal with our illness and with the child? Sometimes no one understands… It was very hard for me to keep going, without money, with a child, and being ill… And now I ask my mother why she didn't help me, nor my brothers, when I needed it… It makes me really angry' (Quote 44:9, mother with SMI, Mendoza)*

- **Supporters are affected by their role**:

Supporters tended to prioritize negative aspects in their valuation of support, summarized in Table 43. In both places, they commented that helping the mother was ***difficult and problematic***. Some, especially in Granada, described the experiences of support in more dramatic ways, including expressions like '*traumatic'*, '*horrible'*, '*terrible'*, '*bad'*, '*hard'*, '*painful'*, '*a continuous agony'*, '*a Calvary'*, '*a jail'* and '*the worst illness someone can have'*. Caregiving constituted for most supporters an ***intense, demanding, long lasting and time absorbing experience***. Sometimes care completely absorbed their lives, and could constitute a ***life changing experience***. Others-especially in Mendoza- highlighted the ***high effort and responsibility*** involved in their role and the overload of work it implied***.***

Table 43
Experiences of support: Negative descriptions. Supporters, both sites of study

	Granada (n=10)	Mendoza (n=12)
Difficult and problematic	3	5
Dramatic expressions ('horrible', 'traumatic', etc.)	7	3
Intense, demanding, long lasting, time absorbing	6	3
High effort and responsibility	5	6
Life changing or life breaking	3	-

Most supporters talked about how their role as supporters affected their lives in various ways (See Table 44), especially in their emotional life, but also social life and physical wellbeing.

Table 44

Experiences of support: Consequences of support on supporters. Supporters, both sites of study

	Granada (n=10)	Mendoza (n=12)
Emotionally affected	8	8
Limitations in social life	3	7
Physical burden	1	2

In both places, the most frequent complaint of caregivers was to feel ***emotionally affected by their role***. Several negative feelings were expressed regarding their role as supporters, especially feeling overwhelmed, depressed, sad, anguished, nervous and stressed, with difficulties to relax or with lack of motivation. Others described to frequently feel afraid, fearing the mother would put the child or herself at risk or would turn aggressive towards the supporter. Some caregivers also expressed feelings of uncertainty, insecurity and instability, reaching the point of feeling they had lost parameters about normality and rational thinking. Many talked about a strong, sad and overwhelming feeling about the child (See Table 45).

> *'There is a saying that even if you are hard, water with time can break the stone… like water when it starts falling, with the years… makes a hole in the stone. And you think: how can a stone have a hole! It's because of so much beating, beating, beating on the same place… I mean, these things will always affect you, even if you are hard…' (Quote 40:56, supporter, Mendoza)*

> *'My personal resources have been drained already. I am exhausted… because it has not been only the last years, I have been fighting with this since she was born' (Quote 24:94, supporter, Granada)*

Table 45

Consequences of support on supporters: emotional burden. Supporters, both sites of study

	Granada (n=10)	Mendoza (n=12)
Feelings of overwhelm, anxiety, anguish, depression	6	5
Fear of mother putting herself, the child or the supporter at risk	2	2
Feelings of uncertainty, insecurity, instability	2	1
Negative feelings regarding the child	3	1

With higher frequency in Mendoza than in Granada, supporters talked about the ***consequences of their role in their social life and activities***. They mentioned difficulties to go out, meet friends, have a partner, study or work because of the intense aid they were giving. One participant in each site of study considered they had neglected care of their own family, paying less attention to their own or their other children.

> *'I had to leave my youngest child aside… poor of him. He was so small and had to go live with his dad… because I could not do it all, I dedicated myself to what I thought was the priority in that moment.' (Quote 46:37, supporter, Mendoza)*

Additionally, some felt ***physically affected*** by their caring role and activities, feeling tired but also becoming severely sick. Some thought their physical illnesses were a product of containing strong emotions.

> *'Sometimes I think that maybe my heart attack was caused by all these problems I was constantly swallowing! Because it is one problem after the other, when you are not expecting it something bursts somewhere.' (Quote 52:92, supporter, Mendoza)*

Many caregivers, talked about the ways in which they tried to deal with these problems in care (See Table 46). They talked about making constant efforts to withstand, get used to, or fight against problems that arose because of the mental illness or in the caring relationship. These ways of dealing with the situation required a slow learning process and strength and sometimes turned out to be impossible or very difficult.

> *'I try to handle it as best as I can but my life is not what I would have liked it to be, evidently… Because at my age, to have such a big responsibility… it requires lots of effort and fight, everyday… Lots of fights, like those fishes, the ones that swim against the current.' (Quote 12:197, supporter, Granada)*

Supporters in both places talked about frequently needing to take ***respites*** of their tasks as supporters, especially when they were feeling overloaded and burdened. Most tried to distract themselves by visiting family and friends or by being involved in some leisure activity.

> *'Often I need to go out a little. Go out, talk about football, change the air… There are moments when my body asks for it, to go to the countryside and walk, run, because… this illness absorbs you, it absorbs you and it is complicated…' (Quote 15:31, supporter, Granada)*

Table 46

Experiences of support: Negative descriptions. Supporters, both sites of study

	Granada (n=10)	Mendoza (n=12)
Efforts to deal with overload	6	4
Need of respites	3	3

4.3.6. SUMMARY OF THE SECTION EXPERIENCES OF SUPPORT

Summarizing the findings of this section, mothers with SMI were considered as the main figure of care of their own children in most families. Given the diverse difficulties they presented, all participants recognized their need to receive support in parenting. Though, supporters tended to consider their aid as more fundamental to achieve an adequate parenting than mothers themselves.

Support in parenting was mainly provided by informal networks of care organized around one main caregiver. Main caregivers assumed most functions and activities of care, accompanied by one or more secondary figures of support that complemented them in their activities. Both, main and secondary caregivers, tended to be members of the mother's family of origin, in general women, followed by partners. Support was in general considered to be a long lasting and demanding activity, requiring a complex organization of activities that addressed mothers in their mothering functions and in other areas of their lives, but also addressed children directly, and aspects of the context like monetary aid and household. Support became even more demanding during moments of psychotic breakdowns, periods during which efforts were doubled to take full care of children while following up the mother, be at home or at the hospital.

Regarding support in the long term, most participants tended to speak indistinctly about support that directly referred to parenting, with support in other areas of the mother's life. Among activities of support directly related to parenting, all participants identified similar themes. Caregivers tended to speak with slight more frequency than mothers about mediating mother-child interaction and being attentive to child's needs, while mothers tended to talk with slight more frequency about supporters directly intervening in childcare. As well, supporters- especially in Granada- tended to describe with more detail than mothers many activities of support that indirectly influenced parenting.

In general, the mother was an active participant of the process, and most participants thought it was important for mothers to be as autonomous and independent as possible.

Several problems appeared in the process of giving and receiving support, especially difficulties in the interaction between supported and supporter, that could end up making support invalid in the eyes of some mothers. As well, difficulties in the interaction and an overload of work related to care, counted among the most common complaints and difficulties caregivers faced regarding their role. Noticeably caregivers in Granada tended to complain much more about the difficulties and burdens associated to their role, than supporters in similar situations in Mendoza. Despite problems and difficulties encountered in support, the great majority of participants highly valued it and thought it was fundamental for wellbeing of mother and child. As well, supporters valued several emotional aspects of support, especially they joy children brought to their lives, and the good relationship with mothers and other family members.

4.4. RESULTS: EXPERIENCES WITH MENTAL HEALTH CARE SERVICES AND OTHER INSTITUTIONS

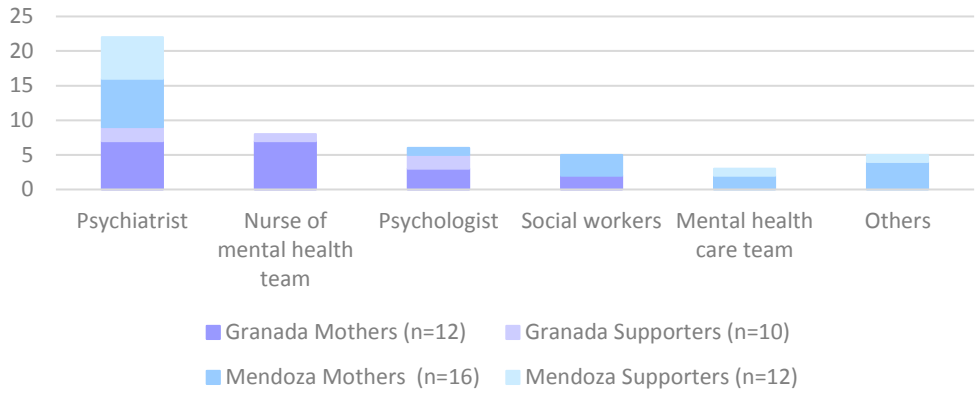
During their accounts, all participants talked about how the health care system and other institutions had influenced their experiences with mental illness, parenting and social support. They mostly talked about mental health care services, but also about educational institutions, religious institutions, police and courts, and state economic aid. These experiences will be described in the following lines.

4.4.1. SUPPORT FROM HEALTH CARE SERVICES

As was explained in the section of quantitative data, mental health care services were organized in different ways in both sites of study. Participants in the region of Granada, Spain tended to receive mental health care in services integrated to the network of primary health care and in line with the principles of community mental health care. On the contrary, most participants coming from the region of Mendoza, Argentina, received ambulatory mental health care in a psychiatric hospital. These differences in the organization of mental health care in both regions was reflected in the accounts of participants in aspects like who they were cared by, whom they considered as a figure of reference in the system, and which were the tasks and interactions with carers.

As can be observed in Figure 9, participants appealed to different ***figures of reference in the mental health care services*** when having a problem or doubt, in general to the professional they perceived as more involved in their care. In Granada, participants tended to mention the psychiatrist but also the nurse of the mental health team as the main figures of reference. On the contrary, participants in Mendoza tended to consider the psychiatrist as the main figure of reference while the nurse was an absent figure in mental health teams. In both places, participants mentioned other professionals involved in formal care, mainly psychologists. In Argentina participants also mentioned therapeutic companions and educational psychologists, and some participants did not recognize one figure of reference but a whole team involved in their mental health care.

Figure 9
Figures of reference in mental health care services. All participants



Participants in both places talked about the ways in which professionals from mental health care services supported them in parenting through their interventions, and the ways in which the organization of institutions affected their parenting. Five themes were identified regarding these aspects, namely: ***direct support in parenting***, ***indirect support in parenting***, ***promotion of social integration***, ***support for supporters***, and ***access to care***.

- ***Direct support in parenting coming from mental health care services***

Professionals of the mental health care services sometimes directly addressed issues about childcare, during consultations or during home visits (See Table 48). ***During consultations***, professionals in both sites of study (especially nurses and psychiatrists) directly asked the mother with SMI about her children and how she was dealing with childcare. They gave advice about childcare and education when a difficulty was perceived, and in some cases, they helped to organize a network of social support which would aid the mother in parenting.

> *'S., the nurse, supports me a lot… she always asks me about the child, about problems… if there has been any problem, how I have been doing… and also doctors… I feel that I had lots of support' (Quote 11:48, mother with SMI, Granada)*

Less frequent, and more common in Granada, mothers received ***support at home*** provided by figures like therapeutic companions, social educators and counselors. Support at home included regular home visits during which professionals directly interacted with children, took care of them during some periods of time, or watched the interaction between mother and child. Additionally, some families in Granada counted with a person to provide company to the mother and aid in household tasks.

Participants which received support at home coming from the formal systems of care tended to appreciate and value it in a positive way, given the relief in the load of daily tasks and the possibility of social interaction it gave them.

> *'C., the therapeutic companion… she sometimes takes the child in the evening and brings her back in the next morning, so that she can go to school. I think well, if she takes her the whole day I can do all what I need more calmly. I start… everything more calm, to organize myself with cleaning, washing, ironing…' (Quote 32:43, mother with SMI, Mendoza)*

On the contrary, two families which received aid at home, one in Granada and one in Mendoza, perceived it as unnecessary. In Granada, mother and supporter of one family thought that they could take good care of their children and complained about receiving an aid which was not needed, while aid in other more fundamental aspects, like economic aid, was neglected. In Mendoza, one supporter complained about social services making several home visits but finally not solving any aspect of the problematic.

> *'Social assistants have been several times to my house, but after that it all keeps being the same' (Quote 38:25, supporter, Mendoza)*

Other participants did not receive ***any support they considered useful for their parental role coming from the mental health care services***. This was expressed with much higher frequency by participants in Mendoza, as show in Table 47.

> *'The hospital does not help me much in my mother functions… they are more focused on me, they focus on me'. (Quote 39:172, mother with SMI, Mendoza)*

> *'No one has ever been interested in… in talking about the topic of children, about raising children, having schizophrenia! No one was ever interested (…) I would have liked it, yes (…) as an escape to know how, how to deal with this situation. But I don't… I have not had much help' (Quote 45:62, mother with SMI, Mendoza)*

Table 47

Experiences with formal health care: direct support in parenting. All participants

	Granada		Mendoza	
	Mothers (n=12)	Supporters (n=10)	Mothers (n=16)	Supporters (n=12)
Issues regarding childcare are addressed during consultations	4	1	5	1
Support at home: aid in childcare, observational visits, assistance in household	4	1	1	1
No useful support in parenting	1	1	7	3

- ***Support from mental health care services that indirectly influences parenting***

With high frequency, participants talked about different aids of professionals that improved their wellbeing and could exercise an indirect but strong influence in their parental role (See Table 48).

Table 48

Experiences with formal health care: indirect support in parenting. All participants

	Granada		Mendoza	
	Mothers (n=12)	Supporters (n=10)	Mothers (n=16)	Supporters (n=12)
Psychiatric treatment as fundamental	3	2	6	2
Complaints about medication	5	6	6	6
Satisfied about professional technical competence, given information, empathic capacity, involvement of family in care	4	4	7	6
Negative experiences: taking decisions without involving the patient, not informing, being rude or intimidating	5	1	5	1

Especially among mothers in Argentina, the ***aid of psychiatrists and psychiatric medication was perceived as fundamental for their wellbeing***. Most participants in both places thought medication was the key for recovering from psychotic relapses, keep stable, and improve mood.

> *'To go to the psychiatrist and having medication every month. I must have it. And a psychiatric treatment, I have to have it.' (Quote 33:68, mother with SMI, Mendoza)*

> *'Now she is fine, she is fine as long as she has adequate medication… Here, about the hospital I cannot complain, because they are all great here, they give her the perfect medication…' (Quote 52:32, informal carer, Mendoza)*

On the other hand, participants in both places ***complained about medication*** not being effective or having had to try many schemes of medication to find an effective one. Others did not like to take medication, frequently dropped out of treatment and complained about the treatment focusing too much on medication. The most common complaint were adverse effects caused by medicines, especially sedation, tiredness and extrapyramidal symptoms which in some cases caused severe difficulties to the mother in her parenting tasks, as was mentioned in the section of experiences of maternity.

> *I have to be… active, active… but now, my medication has been changed and… in the beginning I am always a little more… more tired, until they regulate it better…*

and then I hope, I hope to get well soon, and… to be able to do things for my child…' (Quote 11:90, mother with SMI, Granada)

Regarding ***professional health care***, many participants in both places expressed to be satisfied with it, highlighting technical competences, dedication in explaining aspects of the mental illness to patients and their families, and capacity to listen and understand. High importance was given to the way in which professionals involved family members in care and the support they gave to solve problems through advices or talks with all members of the family. On the contrary, a few participants from both sites of study felt that professionals involved themselves in family issues taking the side of the opponents.

'The good things I have are the nursery, the hospital and all the aid it gives me, that the doctor is there, the social worker… the psychologist was also there, she was really nice, and… and all that help they give me and all that… interest they have in me… for me it is really important.' (Quote 39:171, mother with SMI, Mendoza)

Negative experiences with professionals were mentioned with less frequency. These included doctors not telling patients their diagnosis, or taking decisions regarding hospitalization or medication without discussing them with the mother. Some felt intimidated by their doctors or psychologists and did not tell them all their experiences about illness, while others experienced rude and discriminative attitudes related to their mental illnesses. These included some professionals considering the mother could not take care of her child just because she had a mental illness, and being menaced by social services to take their children away without offering other types of aid.

'I used to receive… the money as carer of my child that has autism, through the Law of Dependency (…) They took it away from me. They took it away from me because of my illness… because they said I could not be carer… because I had an illness' (Quote 8:35, mother with SMI, Granada)

- ***Promotion of social integration***

In both places, some participants talked about the formal health care system promoting the mother's social integration (See Table 49). In Granada, social integration tended to be organized in ***institutionalized programs with specific goals and aims***, like FAISEM (Andalusian public foundation for social integration of people with disabilities), or labor integration programs organized by municipality.

'In the center where I go, we are protected… because there are also employment technicians, then they look for jobs for you.' (Quote 13:117, mother, Granada)

On the contrary, most participants in Mendoza and some in Granada were using ***community resources*** that did not have specific rehabilitation goals, like sewing classes, gym classes, etc. Only one mother talked about participating in community activities with her child.

'I am going to… to sewing classes, I started this year… in a school. And… that entertains me, does me good. The doctor suggested it. He first suggested a physical activity, and in… in the community center they had gym, and I went. And it was also good for me.' (Quote 30:31, mother, Mendoza)

In general, mothers tended to ***positively value*** all types of activities in which they participated, because it gave them the possibility to be active and interact with others. Some expressed a ***negative opinion***, found the courses useless, boring, and complained about the ambient and type of people they met there. Some mothers of both places that assisted to group activities had difficulties to participate in them, feeling uncomfortable to talk about their problems in front of others or not feeling identified with other participants of groups.

'I was told that I could go to a group for free, a raising group that exists… but I did not contact them again, because of shame! (…) I was ashamed because all listen to you, and of course, they think something. I have been in groups, once in a group there was a… a guy that could not stand me because he said I was not properly dressed, and that made him reject me. Then I am afraid that it will happen again, and I did not want to go… but it would be good, actually.' (Quote 39:29, mother, Mendoza)

Table 49

Experiences with formal health care: promotion of social integration. All participants

	Granada		Mendoza	
	Mothers (n=12)	Supporters (n=10)	Mothers (n=16)	Supporters (n=12)
Institutionalized programs for social and labor integration	3	3	-	-
Community resources	2	3	4	3
Satisfied with social activities promoted	2	1	6	-
Not satisfied with promoted social activities	4	2	3	-

- ***Support for supporters***

Caregivers in both sites of study talked about the way in which mental health care services and professionals acknowledged their role and needs as supporters (See Table 50). In Granada, some participated in ***support groups for caregivers*** organized by health care institutions or family associations. Nevertheless, the majority did not receive any stable and organized aid or support related to their care function. Some did talk about receiving ***emotional support from health care system in a non-regular way***, when they talked about their feelings with different professionals that were involved in the care of the mother or the child. On the contrary, others did not think they needed any type of professional support.

> *'The one that was dealing with the support, that is me, her husband, well… in the beginning it was complicated… Over time, it has been fifteen years, over time you learn little by little, in group therapy… where we are with… other professionals. There they teach you how to deal better with the illness.' (Quote 15:4, supporter, Granada)*

A fundamental support most participants required from mental health care services and professionals was to receive ***information about mental illness***. This was considered a very important aspect that would allow them to adequately fulfill their role, as most of them did not have any type of information or previous experience about mental illness. Many talked about professionals giving them information about different aspects of illness including manifestations, probable evolution and characteristics of treatment. But many complained about not having received any information about the illness, having received partial or insufficient information or having received the information too late or too slowly.

> *'I had no idea this could happen… It was a complete ignorance, and the lack of information… I think it plays an important role. Because especially the uncertainty you have… you don't know anything, you don't know what is happening, why… the causes, or… what can come… because you ignore all.' (19:11, Supporter, Granada)*

Table 50

Experiences with formal health care: support for supporters. All participants

	Granada		Mendoza	
	Mothers (n=12)	Supporters (n=10)	Mothers (n=16)	Supporters (n=12)
Group support	-	2	-	-
Emotional support from professionals	-	1	-	2
Receiving information about mental illness	-	4	-	3
Insufficient, late or no information	-	6	-	2

- ***Organization of services and access to care***

Many participants in both places spontaneously complained about the organization of services and access to mental health care. They expressed dissatisfactions because ***services were not providing care in a regular way***. Their treating professionals were changed frequently, or some services -like group therapy or therapeutic companion- were suddenly interrupted. Several patients in Mendoza and less in Granada expressed ***difficulties to access services they needed***. Reasons for this included health and rehabilitation services being too distant, not having enough places for all users, and users having difficulties to orient themselves in the health care system or not having enough time to assist with regularity. As was mentioned in the section of experiences of maternity, the fact of having children created some ***restrictions in care***. Mothers lacked time to look for and receive care for themselves, and some therapeutic options like hospitalization were avoided because they needed to take care of children.

> *'When I have to come here to the hospital, I have to take two buses… I get up at five in the morning'. (quote 47:8, mother with SMI, Mendoza)*

Table 51

Experiences with formal health care: access to care. All participants

	Granada		Mendoza	
	Mothers (n=12)	Supporters (n=10)	Mothers (n=16)	Supporters (n=12)
Services do not provide care in a regular way	2	1	1	1
Difficulties to access care because of distance, lack of resources or lack of time	3	-	6	1
Difficulties to access care because of having children	1	-	2	-

4.4.2. SUPPORT FROM SCHOOLS

Mothers in both sites of study, but with higher frequency in Argentina, talked about support received by teachers and schools in their parenting roles (summarized in Table 52). Teachers helped them in educational issues with children through ***parent meetings or*** *through* ***personal meetings.***

> *'I have always been to parent meetings. It was not difficult to understand, no… I used to tell my mother… Some things I could not understand, and I used to tell my mum to come with me to the meetings… she helped me, we went both…' (Quote 35:38, mother with SMI, Mendoza)*

Teachers also intervened when they noticed a problem in the child, calling the mother and ***referring the child to a mental health care consultation***. Additionally, some mothers in both places talked about school giving special ***support to their children when they had difficulties in learning***. In Argentina, many mothers highlighted the aid school gave them with ***feeding*** their children, since many stayed at school to have lunch.

> *'He is in a support class in school, yes, with other children that have some handicap (…) And I also receive support about how to take care of him… The teacher, she is always in contact with my husband, through the mobile phone and so…' (Quote 14:43, mother with SMI, Granada)*

> *Another very important thing is that she goes to the nursery. A place of emotional containment, because the teacher is an angel, really good… there they feed her, she does activities, so… the nursery is very important.' (Quote 39:235, mother with SMI, Mendoza)*

Two participants in Granada complained about insufficient or inadequate intervention from schools when the child had a problem. They talked about teachers noticing problems too late or intervening only if something very severe happened. On the other hand, two mothers in each place had the possibility to receive aid in parenting but did not accept it, because of mistrust, discomfort to participate in group meetings or difficulties to understand the given information.

> *'You don't have… in school they have what they have, they don't have that aid… I have spoken for example with the counselor and she said that unless there is a serious problem they will not intervene with children.' (Quote 12:182, informal carer, Granada)*

Table 52

Support from schools. All participants

	Granada		Mendoza	
	Mothers (n=12)	Supporters (n=10)	Mothers (n=16)	Supporters (n=12)
Meetings with parents	2	-	6	-
Referral to mental health care	1	-	4	-
Support for learning	2	-	2	-
Feeding	-	-	3	-
Insufficient or inadequate aid in parenting	4	-	2	-

4.4.3. DISABILITY PENSION AND OTHER GOVERNMENTAL ECONOMIC AIDS

Disability pensions were the most common economic aid received by mothers with SMI in both sites of study (See Table 53). As was seen in the section of socio-demographic characteristics, it was more often received by mothers in Mendoza than in Granada. Most participants highly valued the fact of receiving a disability pension, which was used to cover basic expenditures like food, clothes and rent, to collaborate in house overall expenditures, or to cover mother's personal expenses. Some participants had a negative opinion about the disability pension, considering it was insufficient to cover all basic expenditures, labelled the mother as a handicapped person, or was inadequately used by the mother.

> *'I am receiving the pension… the doctor made me do the pension. So with that… our expenses are covered, at least I can buy some things…' (Quote 30:76, mother with SMI, Mendoza)*

Additionally, state was giving ***other types of monetary aid*** in both countries, especially in Argentina. These aides included a monthly amount for children and monthly food tickets in Argentina, and monthly economic aid for women suffering from domestic violence in Granada.

Other types of economic aid included ***provision of free transportation and food***, more frequent in Argentina. Food was provided in a regular basis by charity organizations in both countries, and by health care centers and schools in Argentina. Free transportation passes were received by some participants in Argentina because they were receiving chronic health care or because they lived far away.

> *'Within all the bad, I am being lucky. I signed to Caritas, I go with my sister in law… we go every month to take our number, we receive our food…' (Quote 13:105, mother with SMI, Granada)*

Table 53
State economic aid. All participants

	Granada		Mendoza	
	Mothers (n=12)	Supporters (n=10)	Mothers (n=16)	Supporters (n=12)
Disability pension	3	-	12	-
Other types of monetary aid	1	-	3	-
Provision of food	2	-	4	-
Free transportation	-	-	2	-

4.4.4. OTHER INSTITUTIONS INVOLVED IN SUPPORT

As can be observed in Table 54, some participants in Spain and more frequent in Argentina, talked about ***spiritual and social support given by church*** to mothers and, especially, to supporters.

> *'I have always tried to help her. Why? I belong to an evangelic church, I am religious. And there you learn a lot about… to see the need of others and help them. So I have always tried to help her and her husband, give them advice…' (Quote 34:8, informal carer, Mendoza)*

Police was mentioned with high frequency as a figure which intervened in case of violent interactions within families, in case the mother had behavioral disruptions or when she needed to be taken to the hospital. Besides these more urgent functions, some mothers tended to invoke the figure of the police to solve minor family problems.

> *'Recently she reported me to the police saying that I was mistreating her, because I recriminated her that she was not taking good care of the house… then she called the police and they came, when I explained what happened, well, they left'. (Quote 42:64, informal carer, Mendoza)*

Some other ***justice and law institutions*** were frequently involved in issues surrounding parenthood, especially in Argentina. For example, family courts or public institutions for protection of rights intervened to arrange custody of the child in both countries, and to request and organize mental health treatment for the mother only in Argentina.

> *'She was only two months old and I was called from the Office of Protection of Rights… A judge of the family court and a social worker talked to me there… good girls… as soon as I had my child they told my father that I could have a personal therapeutic companion…' (Quote 41:76, mother with SMI, Mendoza)*

Table 54

Support in parenting coming from other institutions. All participants

	Granada		Mendoza	
	Mothers (n=12)	Supporters (n=10)	Mothers (n=16)	Supporters (n=12)
Religion and church activities	-	1	3	4
Police	2	1	3	1
Judicial institutions	1	1	4	2

4.4.5. SUMMARY OF THE SECTION: EXPERIENCES WITH MENTAL HEALTH CARE SERVICES AND OTHER INSTITUTIONAL SUPPORTS

Among health care services, the role of women with SMI as mothers was not acknowledged as strong as within informal sources of care. Nevertheless, many mothers received some support in parenting by professionals of the mental health care system, mainly in the form of advice or home visits. This was much more frequent in Granada than in Mendoza, where most mothers complained about not receiving any support in their role as mothers. Participants from all groups additionally talked about how other type of interventions of professionals could still influence their parenting, especially medication that helped them control symptoms that were disruptive for parenting. On the contrary, others complained about medication causing difficulties in parenting, and had additional complaints about professionals having restrictive or stigmatizing attitudes towards the mother with SMI. Some talked about difficulties to access care, many times related to their limitations in time and mobility associated to having a child. Supporters additionally talked about the support the mental health care system gave them in their role as carers, most of them complaining about lacking information and support in their role.

Schools also provided some support in parenting, especially in Argentina. Mothers explained how teachers gave them advice about childcare, and helped them to look for help in the health care system when needed. As well, participants in Argentina talked with higher frequency than in Spain about support given by other institutions. These included churches, police and courts, and especially state economic aids in the form of disability pension, food, transportation and other types of monetary aids.

4.5. RESULTS: NEEDS OF SUPPORT IN PARENTING

Participants from all groups extensively talked about unmet needs of support in several areas of their lives related to parenting. They talked about several types of needs, which were classified in two main groups in line with the organization of the previous results: needs of support of the mother in areas not directly to parenting (and which have an indirect effect on her role as mothers) and needs of support in their mothering role. As well, needs related to formal systems of care and needs of supporters will be included in this presentation of results.

In general, there was great coincidence in the themes identified among mothers and supporters in both countries. Supporters tended to talk with more frequency about needs that were already fulfilled by them, being more reluctant to talk about uncovered needs. Mothers on the other hand tended to highlight unmet needs and desires, and expressed some needs supporters did not talk about in relationship to express themselves and be accepted by society. This will be explained in more detailed in the following pages.

4.5.1. NEEDS OF DIRECT SUPPORT IN PARENTING

Participants from all groups talked about different types of support in parenting that mothers with SMI were needing, summarized in Table 55.

Table 55
Unmet needs of support in parenting. All participants

	Granada		Mendoza	
	Mothers (n=12)	Supporters (n=10)	Mothers (n=16)	Supporters (n=12)
Direct interventions regarding childcare and education	6	9	11	3
Economic support	5	6	7	5
Orientation, advice, guidance	5	3	5	3
Motivation to perform mothering tasks	-	5	-	-
Company and general supervision of mother's activities	2	2	3	1
More stimulation for the child	-	1	1	2

Even when most mothers received support in childcare, many expressed the need of ***supporters intervening more directly in childcare and education.*** These included more instrumental support to take care of children, especially in school related tasks.

> *'I am fine, I don't need support for me, my child needs it more. For his studies, for whatever, some private classes…' (Quote 17:28, mother with SMI, Granada)*

Only in Mendoza, mothers that did not count on *supporters to take care of children during some periods of time* expressed the need of that type of aid so that they would be able to take care of other responsibilities or have time to rest. Many participants in both places, but especially supporters in Granada and mothers in Mendoza, considered mothers needed *more direct interventions of supporters in the education of children and in the setting of limits*.

> *'I would like to have some help with children, for example if I need to go to the doctor I have to let the children here… because they get tired, and want this, want that, and I cannot keep an eye on them… Yes, I would like an aid like that, yes, to be helped… to take care of them… and prepare food, and clean.'. (Quote 49:66, mother with SMI, Mendoza)*

In second position, several participants from all groups talked about the ***need of mothers to be economically supported by their families or partners***, and considered this type of aid one of the most important they received or should receive.

> *'In the beginning, what you mostly need is economic support. Because if you don't have it… in the beginning, because of the medication and the illness, it is very difficult to find a job and keep it.' (Quote 2:94, mother with SMI, Granada)*

Following, participants from all groups requested ***more orientation about care, education and disciplining of children, orientation about solving problems or face difficulties with their children and orientation to organize daily routines of the child***. Supporters additionally talked about the ***need of mothers to be motivated to perform their mothering tasks*** and some considered support was needed as a general supervision of mother's activities.

> *'' It would be good for her… to receive more explanations about how to take care of a child. Because she does not know how' (Quote 42:73, supporter, Mendoza)*

*As was sho*wn in Table 55, other needs were identified with less frequency by participants in both groups, including the mother's need to have ***company*** while she was with the child and the need of counting with ***more social interaction and stimulation for the child***.

4.5.2. NEEDS OF SUPPORT INDIRECTLY RELATED TO PARENTING

Needs that indirectly affect parenting were identified with high frequency in all groups of study, as shown in Table 56, and explained in the following paragraphs.

Table 56
Needs of support indirectly related to parenting. All participants

	Granada		Mendoza	
	Mothers (n=12)	Supporters (n=10)	Mothers (n=16)	Supporters (n=12)
Activity and independence	9	7	13	4
Emotional support and relationships	12	7	9	3
Mood and mental wellbeing	9	8	7	2
Aid in household	8	1	2	-

One of the most frequently expressed needs among mothers were the needs of ***being more active, feeling useful, productive and being more independent and autonomous***. Informal carers, especially in Granada, mainly talked about the ***need of mothers to be constantly motivated to perform their activities*** in general, and in mothering tasks especially (See Table 57).

Some mothers related the need of more activity to the sphere of maternity, wanting to *be more active in their child's care and education*. Nonetheless most linked more activity and productivity to the *need of working or studying*, as well as *having economic independency*. Some mothers also expressed the need of counting with *models of identification* to feel empowered and motivate their independency, or models of identification for parenting, a need which was met through interaction with other women, or with own parents.

In the moment of the interview most mothers expressed to have the need of work and economic independency unmet, except for some participants who had work. Among these, most counted with jobs where they felt protected and understood in their difficulties. Some narrated moments in the past when they could meet the need of work and economic independency, and how this positively influenced in their mood, family relationships, and mothering role.

'I noticed some improvement when I started to go to sewing classes, I was using my head for something… was distracting myself more. I felt… better, with myself, because I was doing something… learning something, doing something.' (Quote 30:78, mother with SMI, Mendoza)

Table 57

Needs of support indirectly related to parenting: activity and independence. All participants

	Granada		Mendoza	
	Mothers (n=12)	Supporters (n=10)	Mothers (n=16)	Supporters (n=12)
More activity	5	3	4	-
Feel useful, productive	3	2	4	3
More independency and autonomy	4	2	5	-
Motivation to perform activities	-	7	-	1
More active in childcare and education	4	-	3	-
Work or study	4	1	2	1
Economic independency	3	-	-	1
Models of empowerment and identification	3	-	1	-

In second place, participants talked about needs related to ***emotional support and relationships***, summarized in Table 58. It can be highlighted that most mothers and their figures of support in both places expressed one of the greatest needs of mothers to be the ***need of receiving emotional support, love and affection***, as well as having ***company and distraction***. Even when most mothers were receiving emotional support, many considered this support only partially satisfied their needs since some emotional needs were not covered or emotional support was present but problematic. In relationship to this, some mothers expressed the *need of having better relationship with their significant others*, and a *need to be understood in their difficulties by their figures of support*. Some participants expressed a specific need of *having a partner* who would give love and support which was unmet, while others expressed a specific need of having *friends or meaningful and fluent social relationships outside family*, which was also unmet. In relationship to this, some participants expressed a strong wish of *having a 'normal' life*, being able to get married and have children, and have children who would have a 'normal' and happy life too.

'I do want a support… a partner… that takes care of me, that will look out for me… Anything like that now I see it as a need, as eating… it is… like if you are more childish, younger. Those needs… you want those needs to be covered' (2:100, mother with SMI, Granada)

Many mothers, especially in Granada, expressed a strong *need of expressing their feelings, experiences and ideas*, and some expressed the *need of sharing experiences with other women in similar situations*. These needs were met by some and unmet by most mothers. When mothers could not express themselves, many related it to their own introverted character, and many – especially in Granada- to previous experiences of stigmatization when talking about their feelings, losing social contacts or being undermined by others. As a consequence, some tended to hide their emotions, ideas and feelings, isolating themselves. These mothers expressed a ***desire of being accepted by society***, considered normal and being able to openly express themselves.

> *'Not being able to talk, that is… very hard… because you don't know whom you can tell things, and you need… a relief, because having it inside, you alone, it is… too much' (Quote 11:81, Mother with SMI, Granada)*

Table 58

Needs of support indirectly related to parenting: affective and relationship needs. All participants

	Granada		Mendoza	
	Mothers (n=12)	Supporters (n=10)	Mothers (n=16)	Supporters (n=12)
Emotional support, love and affection	7	4	2	1
Company	5	-	4	-
Improve relationship with significant others	3	-	4	-
Be understood by figures of support	4	1	1	-
Having a partner	2	2	3	1
Social relationship outside the family	5	-	1	-
Normal life for them and their children	2	1	1	1
Express themselves and share their experiences	8	-	3	-
Being accepted by society	2	1	-	-

Mothers also tended to talk about their ***need of improving their mood and relaxing***, as well as ***improving their self-esteem and feelings of emotional maturity***, which were unmet in the moment of interview (See Table 59). Most participants talked about different ways in which mothers could feel better, especially through activities out of their homes like gymnastic or workshops, through social interactions, or finding time for themselves to do any activity they enjoyed. Especially mothers in Mendoza talked about needing a calm environment at their homes, without stress nor discussions to improve their mood and keeping stable. Less frequently, participants talked about needing medication to improve their mood. Close to those topics, some participants expressed a need to keep stable in the mental illness and some expressed a wish of being cured of the disease.

'I would like to improve my mood, not be so nervous, not have so much anxiety…' (Quote 3:91, mother with SMI, Granada)

Table 59

Needs of support indirectly related to parenting: mood and mental wellbeing. All participants

	Granada		Mendoza	
	Mothers (n=12)	Supporters (n=10)	Mothers (n=16)	Supporters (n=12)
Improve mood, self-esteem, emotional maturity	7	3	4	-
Mental stability	3	3	1	1

Another theme frequently expressed by mothers, and not so much by supporters, was the ***need of receiving aid in household*** so that they could rest more and devote more time and energy to their children (As was shown in Table 56).

'I would have liked to have someone to help me in… because for example, now, I cleaned… cleaned the house that was a disaster… I would like someone to help me clean… to help me do something. Especially cleaning, so I can take care of my children, and go out… because I don't go out, anywhere...' (Quote 49:42, mother with SMI, Mendoza)

4.5.3. NEEDS OF FORMAL CARE

As was mentioned in the previous chapter about experiences with formal systems of care, most participants were satisfied with the care they received regarding the mental illness, as well as with the orientation they received regarding child education and care. Some participants thought they had all the support they needed from formal systems of care, while others expressed some areas where they would appreciate to receive more care. These areas are summarized in Table 60, and explained in the following paragraphs.

Table 60

Needs of formal care. All participants

	Granada		Mendoza	
	Mothers (n=12)	Supporters (n=10)	Mothers (n=16)	Supporters (n=12)
Psychological support for mothers	5	2	3	1
Psychological support for children	-	2	-	1
Workshops and activities for mothers	2	1	-	4
State economic assistance	1	2	1	2
Daycare for children	-	-	1	1
School support for children	1	-	1	-
Home assistance	2	1	-	-

The most important theme identified as non-fulfilled need from the formal system of care was the ***need of psychological support***, expressed by mothers and supporters in both sites. Psychological support was required by the mother for themselves, in individual or group sessions, to talk about their experiences, deal better with daily life problems, improve communication with others and learn how to deal better with childcare. Some supporters additionally thought that children needed psychological support to deal with the problems brought up by the mother with severe mental illness.

> *'I would like therapy meetings, to talk to people so that they tell you… what to do, all that… about how you can change, how you can see things in a different way' (Quote 1:33, mother with SM, Granada)*

On the contrary, some participants considered that they did not need to talk about problems with professionals and that they did not no need orientation regarding childcare coming from the formal health care system or social services, expressing some levels of mistrust.

> *'No, no, there are things that… no, I don't know. Maybe yes, they help, but as long as me and my wife are here, she will not get a better help than ours, you see? I don´t know, maybe, people say psychologist help, and this and that, I… don´t know if it can be so, because I know who I am and who my children are… and before my father used to just look at me and… no psychologists existed before… there were not so many things as now' (Quote 52:94, supporter, Mendoza)*

Second themes in frequency were the need of workshops for mothers and state economic assistance. ***Workshops for mothers*** were requested so that they would be more active and motivated, and was mostly expressed by supporters in Mendoza. The ***need of receiving state economic assistance*** in the form of *monetary aid*, like a disability pension, was especially mentioned by supporters. The need of other types of economic support was mentioned with less frequency, especially *housing* for women with children.

> *''What is mostly needed is economic support, at least for one of the children' (Quote 9:20, supporter, Granada)*

Other themes expressed with less frequency regarding support coming from formal systems of care were the ***need of daycare for children or school support for children***, the need of ***counseling about reproductive issues for mothers***, or the need of ***home assistance for domestic tasks***.

4.5.4. NEEDS OF SUPPORTERS

Caregivers in both sites of study expressed own needs regarding their role and activities as supporters, including relief of their emotional load, information about mental illness, instrumental support, emotional support and other needs, all of which are summarized in Table 61.

Table 61
Needs of support. Supporters, both sites of study

	Granada (n=10)	Mendoza (n=12)
Relief emotional load, through respites and time for themselves	4	6
Information about mental illness	6	2
Instrumental support (household, administrative issues, instrumental childcare)	2	4
Emotional support	1	4
Others:		
- ***Patience***	1	2
- ***Good health***	1	2
- ***Adequate economic conditions***	1	3

In relationship to the feelings of overload and burden that most supporters experienced regarding their role, one of the most important needs they expressed was to ***relieve themselves from their emotional load***. To materialize their relief most participants talked about needing to distract themselves and enjoy some activity they liked. Needs of respite were partially met by most supporters, while in general they required *more time and space dedicated to themselves to be able to rest and be involved in the activities they enjoyed*. A few supporters mentioned this as the need of '*having a life of their own'*.

Many participants felt they lacked the ***emotional support*** they needed from others including their partner, family members and friends. A few found this type of support covered by group therapy, while others did not think they needed any type of professional support.

> *'It would be good if we had… it is nice to relief from the pain and… have another communication… for example, like when it all started, I was going once a week to my sister's or my son's house. And it was something different, the atmosphere. I was leaving for the weekend… it is not like being here all day inside the house….' (Quote 4:94, supporter, Granada)*

In second place, many considered they needed ***more information about the mother's mental illness*** regarding diagnosis, causes and prognosis, explanations about behaviors they considered pathological, and second opinions about treatment. Most supporters did not have these needs met, or considered they had been met too late. Mots thought information should arrive when first signs of illness appeared.

> *'What you mostly need at the beginning is information, because you have so much uncertainty about things… and doctors do not tell you so much… So, to understand a little more the process that is going on. Just to know what is happening, the causes…' (Quote 19:61, supporter, Granada)*

Other unmet needs supporters expressed with high frequency, especially in Mendoza, were their ***need to be relieved from instrumental household tasks, administrative issues and especially from all type of instrumental support they gave to the mothers with SMI***. Others needed to talk about their problems with someone to receive ***advice*** on how to deal with them.

> *'I would have needed more help of the family… but… I did not have it… they could have offered more help, ask if I needed something' (Quote 48:19, supporter, Mendoza)*

With less frequency, some mentioned ***other types of need*** which included the need of having patience to tolerate problems brought up during support, the need of maintaining a good health and physical integrity to keep their tasks, and the need of having good work, income or economic aid to cover all expenditures related to the mother and the child.

4.5.5. CONCLUSIONS OF THE SECTION NEEDS OF SUPPORT IN PARENTING

Summarizing the results of this section, we can observe that participants from all groups extensively talked about needs of support that were unmet or about the need of improving support they were receiving. All participants talked more about needs indirectly related to parenting than about direct needs in parenting. The most frequent need expressed among all participants was *mothers to be more active, independent and autonomous*, followed by needs related to *emotional support and relationship with others*. Nonetheless, when observing the accounts within each group we can observe that it was mostly in Mendoza were mothers and supporters talked with higher frequency about activity and

independence. Meanwhile, needs related to emotional aspects and relationship with others were more frequent in the accounts of mothers in Granada.

Being more active and independent was referred sometimes to childcare and education, but mostly to work, study and having economic independency. Supporters in Granada especially stressed the fact of mothers needing motivation to be active. Regarding needs related to emotional and relationship aspects, it is noticeable that even when most mothers counted with emotional support, they found it necessary to improve several aspects of it. Mothers especially talked about being understood and being able to express themselves, to expand the network of social bonds beyond family and to improve relationships with their significant others. Need of improving mood and mental wellbeing was mentioned by mothers and supporters in both places in third place. Finally, aid in household was named by some mothers in Granada, but almost not mentioned by participants of other groups. Needs in parenting were identified mainly regarding more need of support in education and setting limits, more instrumental support in childcare, economic support and more orientation and advice about childcare. In Granada supporters additionally talked about the needs of mothers to be constantly motivated to perform childcare tasks, in a similar way as they talked about needs of motivation in other areas of their lives.

From formal systems of care the most frequent need identified by mothers was to receive psychological support. On the other side supporters in Granada considered they needed to receive more information about mental illness from professionals of mental health care, while supporters in Mendoza talked with higher frequency about mothers needing workshops and activities to keep active. Other needs mentioned with less frequency were state economic assistance, psychological support for children, home assistance and daycare or school support for children.

Finally, about half of supporters in both places talked about needing respites and time for themselves so to relieve their emotional load and stress associated to their role as supporters. Following, caregivers talked about needing more aid of others to perform some instrumental tasks associated to support of mothers and this was more frequently mentioned in Mendoza than in Granada. In Mendoza, supporters additionally talked about needs they had to be able to perform their supporting tasks and they mentioned some personal characteristics and material resources. This was expressed with less frequency by participants in Granada.

CHAPTER 5
DISCUSSION

CHAPTER 5:
DISCUSSION

5.1. DISCUSSION OF SOCIODEMOGRAPHIC CHARACTERISTICS AND CONTEXT

Regarding clinical and treatment aspects of mothers in both countries, the most relevant finding refers to the difference in the type of formal care they received, with the great majority of mothers in Granada being cared in community mental health care centers while in Mendoza the great majority received care in ambulatory services of psychiatric hospitals. The different organization of mental health care in both countries can explain the different involvement of professionals and extended participation of community mental health care units in the effective recruitment of participants in the region of Granada when compared to Mendoza. In Spain, the recruitment done fully trough community mental health units and nurses of mental health care teams reflects the typical organization of mental health care in the region of Andalucía. This is based on a communitarian model, integrated to the primary health care network and provided by multidisciplinary teams were nurses play a central role (Torres Gonzalez, 2012a; Valmisa Gómez de Lara et al., 2008; España. Servicio Andaluz de Salud, 2011). On the contrary, recruitment in Argentina was possible in its majority through psychiatrists of one of the main psychiatric hospitals of the region of Mendoza. As was seen in the results, primary health care centers almost don't provide care for population with severe mental illness. This also reflects the typical organization of mental health care in Argentina which is based in hospital psychiatry, with less integration in primary health care networks and less development of community and rehabilitation services (Saldivia, 2013).

Noticeably, more mothers in Mendoza had started with symptoms in a younger age than mothers in Granada. In both regions, the majority of mothers had an onset of illness after having children. Among women that had an onset of illness before having children, the proportion was slightly higher in Granada than in Mendoza (25% vs. 18.75%). The presence of more environmental risk factors among women in Mendoza might be associated to an earlier onset of illness, when compared to mothers in Granada. Social adversities, including unemployment, low educational status, low income and being single, have been associated to a higher risk of schizophrenia and might precipitate an earlier

onset of illness (Bosanac, Buist, & Burrows, 2003; Dean & Murray, 2005). Furthermore, it is possible that women in Granada with an earlier onset of illness had better outcomes and were better integrated socially than women in Mendoza, which would allow them to have children even when having a mental illness already set off. Similar rates of personal and social performance are probably not representative of the whole population of people with SMI, but more characteristic of the subgroup of mothers with SMI that probably had not had strong deficit or deterioration associated to their illness and could maintain good levels of performance in daily life and social activities, including having partner and an active sexual life.

Regarding socio-demographic characteristics of mothers in both places, most findings point to a situation of vulnerability in multiple areas of their lives, including difficulties in social and family integration as well as labor and economic integration. These findings confirm previous findings of authors like Bee et al. (2014), Montgomery et al. (2006), Fraser et al. (2016), Perera et al. (2016) and Nicholson et al. (2001) which described context and circumstances of life of mothers with SMI as unfavorable, turning them into one of the most vulnerable groups in society.

Some conditions of vulnerability appeared with higher frequency between mothers in the group of Mendoza than in Granada, including higher proportion of mothers that were single or separated, lived alone and were not working. The high number of participants that were married in Granada in comparison to Mendoza, could be interpreted as a sign of better social integration. Nonetheless it is also possible that the number of separations increases among time, being higher in Mendoza since interviewed women were of older age than in Granada. The higher proportion of single or separated mothers in Mendoza can also explain the higher rate of women living with their family of origin when compared to mothers in Granada.

Number of children was another important difference between both groups, women having more children in Mendoza than in Granada. This could be explained by the difference in ages of mothers, but also might represent the general tendency of having less children in Spain when compared to Argentina. In fact, fecundity rates of women in both groups was similar to each country rates, which was of 2.19 children per woman in Argentina in 2012, and 1.49 children per woman in Spain in the same year (WHO, 2014). This similarity reinforces the works of authors like Bonfils et al. (2014) and Nicholson, Biebel, Katz-Leavy,

and Williams (2002) that have observed similar rates of parenthood for people with SMI when compared to the general population.

In both countries, most mothers were in a situation of poor working integration. In Granada, a higher proportion than in Mendoza was working or was unemployed but looking for a job (See Table 7). The ones working, were generally doing it under disadvantaged conditions characterized by temporal or part-time jobs, in areas of low remuneration. We can also observe an insufficiency of social and mental health services to guarantee measures of working integration for people with severe mental illness, having some benefits and programs that only reach some of the affected people. Most mothers in Granada were not receiving a disability pension, probably because the social integration policies try not to categorize a person with SMI as disabled. The problem is that many mothers turned out to have no job or low paid jobs and were not receiving any monetary aid, leaving them in a situation of economic dependency which is an additional factor that increases their vulnerability. In Mendoza, the situation of low labor integration was more severe than in Granada, with only one participant having a paid job, in a family company. In this region, much more participants were receiving disability pension, but no institutional interventions or programs were mentioned to improve labor conditions.

Most mothers in both places considered themselves to have a good standard of living regarding economy. Economic difficulties were present in an almost equal proportion in both groups, but in Mendoza the situation was more severe since half of families of women with SMI were not reaching the minimum monthly wages, a situation that happened with less frequency in Granada. Besides the presence of economic difficulties, it is important to highlight that most mothers in both places did not have economic independency. Most of them did not have own incomes, or if they had an income most were not handling it, nor any money or expenditures in their homes. Noticeably, only two mothers directly complained about this situation and problematized the fact of not being able to maintain themselves and their children by their own. These findings show that most women were in a situation of economic vulnerability, either by economic difficulties or economic dependency.

Positive aspects in contexts and life circumstances of mothers included all mothers but one in Granada having formal education, and most mothers living in company of partners or family of origin. Other studies (Savvidou et al., 2003) have previously showed that among people with SMI, the one that are parents tend to have more social support than

the ones that do not have children. There is no available information about the presence and amount of social support among mentally ill individuals that do not have children in the same regions in which this study was performed, so it is not possible to confirm if mentally ill women with children had more social support than their counterparts without children. In relationship to this, some participants in both regions of study did refer to have moved into their families' homes and achieved a stable environment only once they had children, which could indicate and confirm previous findings that having a child increases the need and availability of support.

Regarding socio-demographic characteristics of informal carers, some differences were observed regarding previous studies and reviews like the ones of Vermeulen et al., (2015); Awad and Voruganti (2008), Lasebikan and Ayinde (2013) and Gutiérrez-Maldonado et al. (2005). These authors showed a high difference in sex distribution of caregivers, with a high majority of women taking on the caregiving role. As well, they showed a high involvement of mothers of patients in caregiving, so that they described a typical caregiver being a woman of around 60 years old, mother of the person with SMI, in half of cases living with the person they care for. In our study, age was similar than ciphers reported by these authors, with slightly lower mean age in Mendoza when compared to Granada (53 years old vs 60 years old) and when compared to previous studies. This was probably due to the young age of two figures of support in Mendoza, which were daughters of the mother with SMI. Differing from other studies, there was no sex difference among carers in Mendoza, and a slight difference in Granada (60% women vs. 40% men). The proportion of partners involved in care was higher than in other studies, while in both countries it was still more common that caregiving was assumed by a member of the family of origin. In this case, many were mothers but in Mendoza more male family members were involved in care, including fathers and a brother. Also, two daughters were caregivers in Mendoza, and had started with their caregiving role during childhood. A higher proportion of caregivers was living with the mother with SMI when compared to the proportion of caregivers that live with the person they care for in other studies. Findings regarding sex difference, kinship and cohabitation with the mother with SMI are probably explained by the fact that our study was focused on women that had children. Probably this group has reached higher levels of partnership and marriage, and as a consequence, has more male cohabiting partners involved in care.

Employment rates were higher in Mendoza, which is probably caused by the presence of younger carers than in Granada, which had a higher proportion of retired participants. Other socio-demographic characteristics show some more vulnerability factors in the population of supporters in Mendoza, where the proportion of married participants was lower than in Granada, more economic difficulties were present and level of education was slightly lower.

5.2. DISCUSSION OF THE SECTION: EXPERIENCES OF MATERNITY

In keeping with literature (Diaz-Caneja & Johnson, 2004; Dolman et al., 2013; Montgomery, 2005; Mowbray et al., 1995; Mowbray et al., 2001; Perera et al., 2014; Reupert & Maybery, 2007; Savvidou et al., 2003), motherhood played a central role in the lives of the vast majority of mothers that participated in the study. They placed high value on maternity and expressed strong and positive feelings about their children which were considered as their purpose in life and a source of motivation, company and support. It is possible that mothers expressed these positive feelings about children to comply with prevalent societal norms in which mothers are expected to love their children unconditionally. Nevertheless, their accounts seem reliable since most identified negative aspects of maternity as well, and most accepted that despite their feelings they had difficulties and needs of their own. Moreover, the view of supporters coincided with the one of mothers regarding their affectionate and caring attitude. Many as well highlighted areas were mothers adequately accomplished tasks with children, especially regarding instrumental tasks.

Two mothers could not express any positive aspect of maternity and felt completely burned out by their child, a finding which has not been described with frequency in previous studies. This finding might reflect a common type of thought in psychosis and severe personality disorders characterized by dichotomous reasoning with a tendency to interpret experiences in terms of all-or-nothing (Lemos-Giráldez, Fonseca Pedrero, Vallina Fernández, & Paino, 2010; Garety et al, 2005; Rector et al., 2011), so that a difficulty is transformed into a total negative experience. It is worth noticing that a dichotomous thinking regarding maternal experiences was not the case for most mothers that participated in this study, most of which were able to express maternity as an experience which included positive and negative aspects. This could indeed be interpreted as a sign of stability and compensation of psychosis, and reflect a capability of producing a coherent

and realistic narrative about motherhood, as has been found by other authors (Savvidou et al. 2003). The recognition of positive and negative aspects of maternity by most mothers in this research contradicts previous studies which described mothers with schizophrenia as denying ambivalent feelings associated to their children (Cohler, Grunebaum, Weiss, Hartman, & Gallant, 1976; Duncan & Browning, 2009). Worth noticing is that ambivalence in this case is not mentioned as pathological symptom, but as the presence of contradictory and conflictive feelings experienced by most individuals towards a complex situation like motherhood (Cohler et al., 1976; Parker, 1997; Raphael-Leff, 2010). Affective ambivalence as a symptom of schizophrenia appears to be more intense, can impede action and is considered as a sign of splitting of functions of affect, also affecting thought and behavior (Sadock & Sadock, 2000; Stefan et al., 2002).

Most mothers tended to be aware of many of their strengths and difficulties, having similar appreciations about them than informal carers. Both groups tended to highlight strengths regarding capacity of protection and affection. Interestingly, many mothers expressed confidence about their parenting abilities in general or in some aspects of parenting in particular, which contradicts previous findings which showed a tendency of mothers with SMI to express low confidence in their parenting abilities (Oyserman et al., 2005; Perera et al., 2014). Higher confidence could be associated to a lack of insight of mothers and the tendency to rate their parenting abilities higher than they actually perform them, as showed by Duncan and Browning (2009). In disfavor of this explanation is the observation that higher confidence was expressed with more frequency in Granada than in Mendoza, where empowerment of the patients is a common goal of formal and informal care. In fact, many supporters in Granada and less in Mendoza, talked about one of their main functions to be the constant motivation and stimulation of the mother. This could suggest that the interventions that tend to empower and create a stimulating environment for mothers were having a positive effect on their perceptions of own strengths and capacities. Although the intention of the research and interview was clarified several times, it could be possible that mothers and supporters strengthened their expressions of confidence and positive abilities in response to feelings of mistrust, fear or surveillance related to the interview. In detriment of this explanation is the perception of the interviewer that most participants had a very positive attitude towards the interview, expressed interest in participating in the study and openly talked about their difficulties.

As was seen in the chapter of results, and in coincidence with previous studies like the one conducted by Savvidou (2003), mothers, as well as supporters, were aware of several difficulties they faced regarding childcare and education. There was a general coincidence among participants of all groups in identifying problems related to education, discipline and control of behavior, feelings of overload and other negative feelings associated to parenthood, and difficulties in the interaction with children. These are coincident with previous findings about the most common difficulties of mothers with SMI published by authors like Nicholson et al. (1998a), Gelkopf and Jabotaro (2012), Oyserman et al., (2005), Duncan and Browning (2009), Riordan et al. (1999), Perera et al. (2014) and Mowbray et al. (2001). The accounts tended to be similar in both countries, while some differences were observed. Mothers felt more overloaded in Spain, and mothers as well as supporters complained more about economic and material conditions, although the economic and living situation was similar for participants in both countries. These findings can be interpreted as a higher awareness of participants in Spain about their conditions of disadvantage, with the pretention of improving their situations. This might be the result of a higher critical thinking promoted by their autonomy focused health care system. On the contrary, while sharing a similar situation, participants in Argentina seemed to accept their situation with higher resignation, having less expectations of change and therefore complained less.

Supporters in both places were more reluctant to speak about difficulties of mothers in childcare, but once they talked about them they tended to have a much more negative view than mothers. It is possible that they were more careful than mothers in the way they talked about these sensitive issues, starting to talk more openly while they gained trust during the interview process. In both places supporters talked much more extensively about difficulties and problems of mothers regarding childcare and, in general, considered themselves to be more involved and responsible for children than the mother herself.

Regarding the interaction of mothers with children, supporters mentioned mothers getting irritated and aggressive with higher frequency than mothers themselves. As well they observed difficulties in the interaction that mothers failed to identify which included mothers acting as a child, having difficulties to stimulate the child, and having inconsistent attitudes with them. Other issues mentioned exclusively by supporters included mothers not being aware of their children's needs and their responsibility towards them, neither being aware of some of their difficulties in parenting. Many supporters adjudicated

difficulties of mothers to the lack of qualities they considered fundamental for parenting, like flexibility and capacity to realize and adapt to children's changing needs, self-awareness, capacity of reasoning and capacity to foresee problems and needs in the future. On the contrary, mothers tended to relate problems of discipline and difficult interactions to characteristics of their children, and in general tended to identify factors that could affect their parenting beyond personal factors- especially having a mental illness-, as was shown previously by Brunette and Dean (2002). The most important aspects mothers highlighted as influencing parenting was the presence or absence of a supportive context, while others mentioned unplanned pregnancies and the appearance of symptoms after birth. Meanwhile, supporters were less prone to mention context as determining parenting.

Differences in the accounts of mothers and supporters were also evident regarding the consequences of the maternal mental illness on children. Supporters were much more detailed in their observations and in general more worried about the wellbeing of children than mothers. Most mothers did not talk about consequences of their mental illness on their children, and the ones that did were mostly from Argentina than from Spain. As well, in Argentina the proportion of mothers that mentioned negative consequences of children when compared to supporters was higher than in Spain, probably showing a higher awareness and more realistic account of difficulties. Some mothers in both places even expressed positive aspects that involved children becoming more mature and responsible. Noticeably, the positive aspects described on children are similar to the positive aspects described by caregivers of people with schizophrenia in the studies of Vermeulen et al. (2015) and Veltman et al. (2002), which included becoming stronger, more empathic and patient through care and interaction with the mentally ill individual. Mothers might focus on those aspects as a way of counteracting the negative aspects of the experiences they talked about in a need to reduce feelings of guilt or to reduce stigmatizing views on their difficulties.

The differences in the accounts of mothers and supporters regarding difficulties in parenting and consequences on children cold suggest a tendency of mothers to deny or to lack complete insight of the situation, being able to recognize some difficulties but not in a complete and thorough way. This finding would support previous studies which have showed lack of insight of mothers into their own difficulties (Duncan & Browning, 2009). Feelings of shame or fear showed in previous studies and especially the fear of having children taken away (Dolman, 2013; Perera et al., 2014), could also explain why mothers

did not talk about negative consequences of the mental illness on their children. Fear or shame nevertheless were not considered as a probable explanation for mothers not addressing some difficulties in parenting, since most did openly talk about other problematic experiences and difficulties where they did seem to have more insight. Additionally, the fact that they tended to explain some difficulties as caused by their children can show a tendency to project their difficulties on others, a characteristic that is commonly observed in psychotic individuals (Duncan & Browning, 2009).

Fears involving children's wellbeing and the possibility of not being able to be with them and properly take care of them emphasize our and other authors previous findings about the high value mothers put on maternity and can explain the feelings of guilt, anguish and fear mothers frequently expressed, and that have been reported in other studies (Dolman, 2013; Perera et al., 2014). Additionally, these feelings might show a tendency of mothers to interiorize a negative image of themselves and their parenting competences, which was verbalized by some mothers as a feeling of lack of strength of capabilities, defining themselves from a deficit-oriented perspective.

In accordance to previous findings of authors like Diaz-Caneja and Johnson (2004). Perera et al. (2014) and Savvidou et al. (2003), the great majority of participants in both places considered that having a mental illness affected the mother's parenting capacities in some ways, especially because of some symptoms of illness and adverse effects of medication. This study expanded information about which were the most limiting aspects of illness. Both, mothers and supporters with no difference among countries, identified anxiety, tiredness, depressive mood and negative symptoms as the most limiting symptoms for mothering tasks. In addition, supporters also talked about cognitive and intellectual impairments as frequently affecting parenting capacities, aspects which mothers mentioned with much less frequency, probably because of lower awareness of those impairments. Tiredness and sedation were the most limiting adverse effects of psychiatric medication, which is understandable if we take into account the amounts of energy and time that are needed for childcare. As well, mothers identified stigmatization associated to mental illness as a factor that could hinder their parenting experiences and activities, and cause them insecurity about their abilities when stigma was interiorized, as has been showed by previous authors (Davies & Allen, 2007; Nicholson, 1998a, Dolman et al., 2013; Savvidou et al., 2003; Perera et al., 2014). Worth noticing is that experiences of stigma were almost not mentioned by supporters, except for a few in Granada that were

aware of this and tried to stimulate the acceptance of the ill person in society. Challenging stigmatizing ideas, a few participants in Spain found a positive aspect of mental illness for their parenting.

These findings suggest that while most mothers could perform instrumental aspects of care in a proper way and relate empathically with their children, within an affectionate relation, they tended to lack capacities of adaptability and agency. These are considered as fundamental for adequate parenting (Rodrigo López et al., 2009; White, 2005; Sallés & Ger, 2011). An important finding in this respect is the tendency of mothers of be aware of the influence of context in parenting, which would suggest that most would be able to look for support in their contexts to overcome their difficulties, even when they are not aware of them. The ability to look for social support, to participate in social networks and use community resources is also indicative of capacity of plasticity in the parental role and might compensate other deficits.

In addition to the description of difficulties and limitations provoked by illness, this study adds the valuation of mothers and supporters about the overall capacity of the mother to take care of their children and the strategies they use to be able to accomplish this. Interestingly most mothers considered themselves to be able to take care of their children in an adequate way despite their difficulties. This finding emphasizes the confidence mother feel in themselves, but most probably reflects the fact that most children were doing well in their particular context were supporters were being helpful to compensate the difficulties mothers presented. To support this assumption is the fact that many women identified social support as a strategy to overcome their difficulties. The final conclusion of supporters on mother's maternal capacities differs from the one of mothers, since most considered that mothers could take care of their children only as long as they had intensive support in childcare, as has been suggested by previous authors like Hearle and McGrath (2000), Nicholson et al., (1998b), Reupert and Maybery (2007) and Perera et al. (2014). This could be a source of problems and conflict in the relationship between mother and supporter that makes supporter be perceived as intrusive for the mother and makes them mutually transgress and challenge their guidelines.

This study also shows that almost in all cases the mothers with SMI and their families discriminate between the capacities of mothers during moments of stability and moments of psychotic productivity, making intense changes in their patterns of care and support. With a few exceptions, all participants agreed that during acute psychotic episodes

mothers could not take care of children at all, because of productive psychotic symptomatology, severe adverse effects of medication and hospitalization, and needed a progressive resumption of their parenting tasks when the episode was over. These findings show a high awareness of mothers of the critical situation they underwent during psychotic breakdowns and explains the worries and fears many expressed about having a relapse.

5.3. DISCUSSION OF THE SECTION: EXPERIENCES OF SUPPORT

5.3.1. Experiences with informal sources of care

It was noticeable that the great majority of mothers in both countries counted with more than one figure of support, and only one participant in Mendoza was an only caregiver. This rate of only caregivers is much lower than the one reported in previous studies. For example, Vermeulen et al. (2015), in their study of experiences of family caregivers in 22 countries worldwide, described a percentage of 36% of only caregivers for persons with severe mental illness. It is possible that worries about children's wellbeing could motivate more people to be involved in care of women with SMI that are mothers. But it is also possible that more people were involved in informal care motivated by the need to provide additional aid to the main figure of support, which had double responsibility caring not only for the mother but also for the child. Nevertheless, caregiving was still assumed with higher responsibility by one person, and a very low percentage of families had caring tasks equally distributed among different family members. Secondary figures of support were more involved during moments of relapses of illness, showing adaptability and capacity of response of the network of care during periods of increased need of care.

During relapses, needs of care varied in quality and required different type of tasks from caregivers. A fundamental task was to notice symptoms of relapse and look for appropriate professional care. This seemed to be a difficult task since it could be perceived as violent by the mothers that did not acknowledge they were undergoing a relapse of illness, as typically occurs in psychotic disorders. The fact that secondary figures of support are many times involved in this function suggests that this can be a too emotionally burdensome obligation for the main caregiver, or that another person not so close to the mother takes on the obligation so to preserve the relationship between the main carer and the mother. Caregivers during relapses were also required to take full care of children, and sometimes manage symptoms and medication before and after

hospitalization, or during the whole relapse if the mother was not hospitalized. When mothers were not hospitalized during relapses, needs of care were much higher and a more complex organization of activities of care was required. These findings suggest that families face an overload of care responsibility during periods of relapse. Formal services should prepare families for these moments in advance, and should assist them more intensely giving adequate information, emotional support and additional instrumental aid when needed.

This study confirmed and expanded previous findings about activities of support for parents with SMI, showed in detail how tasks were performed, and provided observations about differences in the results of mothers and supporters and among sites of study. One important finding refers to the two main categories in which participants spontaneously grouped their accounts, namely activities that were directly related to parenting and activities that were not related to parenting but indirectly exerted an influence on it. Participants of all groups made this division, showing a comprehensive vision on care and maternity, acknowledging that the parental role can be affected by several aspects of the mother and her context.

All groups identified the same themes within each category. Worth to notice is that the main activities of support directly related to parenting highlighted by mothers and caregivers, coincide with the areas they had described as more problematic in parenting (discipline, interaction with children, lack of adequate material conditions).

In areas of support not directly to childcare, it can be observed that supporters, especially in Granada, extensively and frequently talked about several areas in which they provided care. In both places the most frequent support they mentioned was reaffirmation and emotional support. But regarding other functions, supporters in Granada were much more fluent and extensive in their accounts than their counterparts in Mendoza. It is possible that they were actually performing more tasks than supporters in Mendoza, maybe because a higher proportion was living with the mother with SMI allowing them to display a higher amount of activities and functions. Also, the fact that more mothers were involved in care in Granada might explain their more integral approach to care, since it could seem like a continuation of their own maternal tasks towards their daughters. Their frequent accounts of being attentive to the mother and promote their motivation and activity, as well as maintaining her health, seem to show a much more permanent involvement in all areas of life of the mother. Clinical data and social performance were very similar among

mothers in both countries, so this would not explain a need of higher involvement of supporters. In this case, the line between support and surveillance seems thin and easy to surpass, but this did not seem the case since most supporters in Granada used strategies to promote the autonomy of the mother. In addition, with such an intense involvement lying on one person's shoulder, exhaustion and burden of supporters seem more probable. This was actually the case with supporters getting more burdened in Granada than in Mendoza.

But it is also possible that supporters in Granada are more educated about their roles as caregivers, which could allow them to identify and name their tasks and functions and value them higher. In relationship to this, it was noticeable how some supporters talked about support using concepts like autonomy and benefits for society, which might reflect a higher information and literacy about their role. Also, supporters in Granada talked with higher frequency than in Mendoza about looking for information to understand the mother and her illness. Additionally, supporters in Mendoza had a higher tendency to consider their situation as part of life, with a normalizing view, which would explain that they could be in fact performing many supportive tasks and activities without necessarily identifying them as support or care.

Themes identified by mothers regarding activities of supporters indirectly related to parenting were similar to the ones identified by supporters. Nevertheless, they talked about these topics with much less frequency than supporters, so that activities not related to childcare directly seemed to be less relevant in their eyes. Some of these activities are subtle and can be displayed during the habitual interaction with the mother, like motivating her to be active and socialize, as well as being attentive to her behaviors and needs. It is possible then, that mothers did not mention these tasks of supporters because they were not aware of supporters performing these subtle activities or, more probably, considered them as part of the normal interaction and organization of activities within a home more than a proper function of care. In fact, many participants among all groups talked how frequent the mother tended to be integrated in her own care and reciprocate aid with her caregivers, supporting the idea that some functions of care were amalgamated within fluent and comprehensive interactions within mothers and caregivers.

Interesting to observe is that most participants of all groups tended to describe active strategies to obtain or to provide support, rather than passive ones. Mothers in Granada tended to involve themselves in the care process starting from asking for help until reciprocating the aid they received. The same happened in Mendoza, where it was

noticeable that most mothers talked about being involved in reciprocal relations of care. As well, in Mendoza some talked about trying to protect the supporters and in some cases distancing from there if there were conflicts, so that again it seems that care activities and functions were integrated in a dynamic of family relations beyond the care relation per se. In Mendoza, mothers also talked about using passive strategies to obtain or accommodate to care with higher frequency than in Granada, a fact which could be probably explained as part of the tendency in that region 'to accept life as it comes'.

Supporters in both sites of study considered that their main strategies to provide support were to get the mother involved in it and to promote her autonomy, but they talked about reciprocal care with much less frequency than mothers. In coincidence with their descriptions of difficulties, it seemed that supporters in general made a lower valuation of the overall capacities of mothers than mothers themselves so that they tried to promote their independent actions but did not consider their interaction reached the point of being symmetrical. The maximum expression of this were restrictive strategies like locking the mother in the house or not involving her into decisions and information, which were mentioned only in Mendoza by one fourth of caregivers. The use of these strategies seems to be related to deficit-based perspectives on mental illness and care, since clinical conditions and social performance of mothers tended to be similar in both sites of study.

The high participation of the mother in care, respect and promotion of her autonomy and the high frequency in which mothers could reciprocate care might be the reason why the great majority of participants made a highly positive valuation of the care they received, even when problems and areas where it was insufficient were described. This is in line with the finding of previous authors who showed that validation of the mother in her role and relationships of mutuality could positively influence parenting (Power et al., 2011).

Participants of all groups identified similar themes associated to problems with support, having coincidence in various aspects of their accounts. As well, most findings were coincident with previous literature that showed problems in the relationship between mothers and caregivers, and in general lack of understanding and inappropriate attitudes coming from supporters (Nicholson et al., 1998b; Savvidou et al., 2003; Zemencuck et al., 1995; Perera et al., 2014). In our study, by far the most important problem identified by all participants were the difficulties in the interactions between caregivers and care receivers. Expanding previous information, this study shows a complex relationship between mothers and caregivers in which both groups tend to perceive the attitude of the other as

inappropriate, causing frequent discussions and quarrels. Disagreements and feelings of displacement were acknowledged as problematic by more than one third of participants, and could also be a source of conflict in the interaction among mothers and supporters. Worryingly, these difficult interactions sometimes escalated to aggression, showing a difficulty to prevent and solve conflicts not only from the mother's side but also from the caregivers.

A finding that has not been commonly described in previous studies was the description of support as helpful but at the same hindering the receivers from involvement in parenting and daily life tasks, independent actions and adequate evolution, not only for mothers but sometimes even for children. It is noticeable how common the feeling of support as double-edge sword was described, as well as the perception of mothers having been displaced in their role as mothers, even when most families made efforts to promote their involvement in childcare and own recovery, as well as their autonomy and independent actions. This shows a thin line and an ambiguous character of support which without having the intention can end up disempowering the person from their own capabilities and diminishing their capacity of agency.

Worth noticing is that most participants did not mention stigma as a problem per se, but they explained how stigma associated to mental illness caused several of the described difficulties and problems in care, from social isolation and difficulties to establish symmetrical social relationships, lack of support and difficult interactions with supporters, to diminished agency not only in childcare but in aspects of household. Stigma caused others not to understand them, not to listen to them, and not to approach them. As well, as was shown by authors like Dolman et al. (2013) and Savvidou et al. (2003), stigma could be internalized and cause mothers to socially withdraw, doubt their own capabilities and be afraid of not being able to accomplish parenting tasks properly and lose their children. Supporters tended to recognize stigmatizing attitudes coming from the environment that isolated mothers and themselves, but did not associate stigma with their frequent difficulties to understand the mother and tendency to feel irritated or impatient with them. Markedly, most of them did recognize the need to have more information about mental illness and how to deal with it.

At the same time, many supporters adjudicated several problems in the interaction with mothers to specific symptoms of mental illness, considering mothers had feelings of mistrust and jealousy, delusional ideas of supporters damaging or stealing children, or

difficulties to control their reactions. The descriptions they made of these cases seemed realistic and not part of stigmatizing views on mothers, showing week points to improve in mothers' evolution, but also in caregivers' knowledge and skills on how to deal with these type of symptoms and manifestations of illness.

Only described by supporters was the complaint about having scarce support for themselves, and difficult social relationships with other family members, as well as having negative feelings about their role as supporters. These findings will be discussed in the following section corresponding to experiences of supporters.

5.3.2. Experiences with formal mental health care

The different organization of mental health care services in both sites of study was evident in the accounts of participants, especially when they talked about figures of reference within the system. It is worth noticing that in Argentina, despite the more traditional organization of mental health care, some type of organizations and interventions corresponding to community care were used, for example interventions coming from a whole mental health team, the participation of a therapeutic companion in care and the use of interventions to promote the social integration of the mother. Nevertheless, these interventions were more common in Granada than in Mendoza. In both sites of study around four in ten families (with a slightly higher frequency in Granada than in Mendoza) received support directly related to parenting during consultations, with professionals acknowledging the maternal role of their patients, giving advice and sometimes helping to organize a network of support for parenting. Others received support at home of diverse type, reaching one third of participants in Granada but only one sixth in Mendoza, where most participants complained about not receiving any support or useful support in parenting. In Mendoza, other institutions like schools were assuming orientation in child care and education for parents, as well as assistance in food. In this way, some deficits of health care institutions were being complemented by schools.

Most caregivers in both areas were satisfied with the overall aid and care received by health care professionals and services, but most of them did not recognize specific aids given to them in their role of supporters. This coincides with finding of previous studies (Vermeulen et al., 2015; Veltman et al., 2002) which have remarked the lack of integration and support for supporters in formal structures of care. Only some participants in both countries but with higher frequency in Granada, highlighted the positive way in which

professionals explained mental illness to the patient and themselves, as well as the positive way in which they were integrated in care, received support to solve problems and received emotional support as caregivers. Additionally, two participants in Granada were integrated in support groups for caregivers organized by health care institutions or family associations. Worth noticing is the role of religious organizations in providing emotional support for caregivers, and charity organizations in providing economic aid. The most frequent aid required from health professionals was receiving more information about the mental illness, its manifestations, evolution and management. Considered especially important was that information be provided early, so that they would be able to deal better with critical situations during the onset of illness.

Even when interventions besides formal psychiatric care were frequent, in both places it was evident that the same services and resources were not accessible for all users within each system. Much of resources and benefits seemed to be randomly allocated in both places. In Mendoza, resources did not seem to be integrated into clear programs and policies of care, and each team had to create individual solutions for each patient. Individual teams in Mendoza also assumed functions that were provided in groups in Granada, for example emotional and informational support for family members. Individually planned solutions caused a great inequality between users, with some benefiting from some services like nursery or therapeutic companion, while most users did not have this possibility. Additionally, the lack of integral programs of care leaves many of the individual initiatives without a concrete end, which was clearly expressed by one participant in Mendoza who complained about having received several home visits that lead to nothing. The situation was different in Granada, where several programs that aim for social integration and support in several dimensions of the life of the patient existed. Despite this, not all users were receiving the same benefits when having the same needs, probably reflecting a lack of resources which made professionals rationalize their use. It seemed that there was no clear policy about allocation of existing resources, with some users receiving benefits they did not consider necessary, and others not receiving what they needed. Probably allocation ended depending from individual efforts and intentions of each professional, as well as individual claims and initiatives to receive care by the users.

Even though mothers in Mendoza were receiving less supportive interventions than in Granada, the general satisfaction with health care professionals and services was higher in Mendoza than in Granada. The opposite was observed for complaints, which were more

common among participants in Granada. The only complaint that was much higher in Mendoza (62.5% of families) was about not receiving support in parenting. It was observed that participants in Mendoza were expecting less solutions coming from the health care system and therefore demanded less from it. It could also be possible that participants in Mendoza were more grateful about the support they were receiving since they could perceive that it came from personal effort from the involved professionals, which tried to organize aid specifically for each mother in response to their particular needs, not counting with extended resources within the system. Finally, but not less important, it is possible that participants expressed positive views given the fact of the interviewer be a former worker of some local health care institutions.

Worth noticing is the high frequency of mothers (more than one third in each country) who complained about problematic interactions with health care professionals which included rudeness, discriminative attitudes and lack of involvement in decision regarding their own care. These types of attitudes made mothers lack trust and reduce their involvement in care, showing an important area of improvement for mental health care services if families wellbeing wants to be supported, as has been mentioned by Perera et al. (2014).

5.3.3. Experiences of supporters

Coinciding with previous literature (Vermeulen et al., 2015; Awad & Voruganti, 2008), supporters in both places tended to make a general negative valuation of their role, highlighting the difficult, intense, demanding and long lasting experience it was. The more dramatic and negative comments were expressed with higher frequency in Spain than in Argentina, although their situations did not seem to be worse. Probably this is associated to cultural differences that influence the ways in which experiences are modulated and expressed.

Emotional burden was common among informal carers in both sites of study. Caregivers expressed negative feelings similar to the ones that have been addressed in former studies of burden (Vermeulen et al., 2015; Veltman et al., 2002). Moreover, worries, pity and sad feelings for the child were a strong additional factor of emotional overload. Limitations in social life were expressed in second place, with more frequency in Argentina than in Spain. This difference might be related to the younger age of participants in Mendoza, which are still planning their life paths with severe limitations. Also, the fact that more supporters were living with the mother with SMI and her children in Mendoza, might

create more restrictions in their social activities. Social burden associated to social isolation and lack of support was mentioned by some supporters, but luckily in both regions around one third of participants expressed to be satisfied and happy about the support they received from their close network of people. This might indicate that families were the person with SMI has children tend to receive more support than others, as was showed in the study of Savvidou et al. (2003). Finally, relationship burden and physical burdens were described with less frequency in both countries, with slightly more frequency in Argentina than in Granada. Economic burden was not mentioned by supporters, except for two, one in each country.

Coping with the situation implied a series of mechanisms used by caregivers. The most frequent strategies they talked about in both places were passive or emotion focused strategies, including effort to withstand and get used to the situation, or distracting themselves from it. With less frequency supporters talked about problem focused strategies, and a few mentioned avoidance and coercion as ways of dealing with their emotional burdens. Most participants in both places expressed difficulties to get by, but only a few considered it impossible and in the end, many expressed to be proud about the way they managed to deal with the situation.

In keeping with previous literature (Vermeulen et al., 2015, Veltman et al., 2002; Awad & Voruganti, 2008), positive aspects of caregiving were described by the great majority of supporters in both places. But positive aspects were associated to other domains than the ones previously described, namely satisfaction brought by children, satisfaction with the aid they were providing, and satisfaction with the support received from others. Positive aspects associated to children were more common in Granada, probably given the more frequent involvement of grandmothers of children in caregiving. Being satisfied with support received from others is in accordance with the lower amount of social burden associated to social isolation as was described above.

It is noticeable that in Argentina there was a general tendency of supporters expressing less burdens as well as less positive aspects regarding their role. The most probable explanation for this is that families understand their situation as one more feature of their lives, and perform their caregiving roles with less reflection and problematization about it. This interpretation could be supported by the observation that more supporters in Argentina than in Granada tended to normalize the situation of support during their accounts, considering it a normal situation of life or partnership. Another observation that

supports this view is that caregivers in Argentina only ranked higher than supporters in Granada in domains were this role provoked clear limitations, like social life and physical health. Underlying cultural differences in the ways illness and suffering are understood, as well as differences in expectations of cure and care, might explain this way of dealing with the situation. But this might also be provoked by families having less information and education about their roles as carers, when information and education can facilitate the reflection and provide a frame of understanding their role and situation.

5.4. DISCUSSION OF THE SECTION: NEEDS OF SUPPORT

5.4.1. Needs of direct and indirect support in parenting coming from informal source of care

Participants of all groups tended to consider all types of needs of mothers as related to their maternal functions and role. All participants explained how their needs as mothers were influenced by their experiences and requirements in other areas of their lives, showing their understanding of parenting as an integrative and multi-dimensional process which is affected by all other domains of life. When asked about the needs of support in parenting that were unmet by current support, mothers in both areas tended to talk about unmet needs with higher frequency than their caregivers. This can be interpreted as a sign of higher dissatisfaction of women with the support they receive, compared to the degrees of dissatisfaction of caregivers about the support they provide.

Regarding the *needs of direct support in mothering roles and functions* the accounts of mothers and informal carers tended to coincide, with the same themes being identified in both regions. All participants highlighted the need of direct help with child care and education, the need of economic support and the need of orientation and advice with respect to childcare. These areas coincided with the areas identified as more problematic in parenting, and with the activities of support highlighted with higher frequency. The demand of satisfaction when support was not being provided in these areas, reinforces their importance and the need of addressing them in any strategy of support. No major differences appeared between the group of mothers in both areas, but some more subtle differences are to observe. Mothers in Mendoza talked about needing supporters to take care of children for some periods of time, a need which mothers in Granada did not tend to mention. It is possible that mothers in Mendoza had a greater need of people taking care of their children given a greater number of mothers that lived alone with children, when

compared to Granada. As well, mothers in Mendoza tended to talk more frequently than mothers in Granada about their need of supporters intervening more in education and setting limits. These differences correspond well with the higher difficulties expressed by mothers in Mendoza in this area. It seemed that families in Mendoza tend to put a higher focus on setting limits as part of child education and care than families in Granada. This, together with a lower stress put on motivation and empowering, might point to an understanding of care more as a function of control of behavior than a promotion of personal development.

It was noticeable how supporters in Granada talked with more frequency than their counterparts in Mendoza about several areas of needs of support in parenting of the mothers they supported. They especially highlighted their needs of having someone intervening directly with children in their care and education, about the need of mothers of being economically supported, and the need of being constantly motivated to perform parenting tasks. These areas coincide with the ones they had identified as most problematic when they talked about difficulties in parenting of the mothers with SMI. Again, their more extended accounts than supporters in Mendoza can be a sign of higher awareness and education regarding mental illness and their roles as supporters. The same observation can be valid for needs of support indirectly related to parenting, areas which again caregivers in Mendoza expressed with less frequency than caregivers in Granada.

Regarding *needs of support indirectly related to parenting*, the most frequently expressed themes among all participants were the need of activity and independence, and the need of improving emotional support and relationships. The need of more activity was sometimes referred to childcare, but especially referred to work, study and having economic independence. It was more frequently described by mothers in Mendoza than in any other group, probably related to the fact that less mothers in Mendoza were working, and less considered themselves to be responsible for household. Worth noticing is that opposite to needing more activity, many mothers in Granada talked about being relieved from some household tasks. Again, these findings might reflect a higher level of activity and involvement in house chores of mothers in Granada than in Mendoza.

Needs related to emotional aspects and relationship with others were more frequent in the accounts of mothers in Granada, even when problematic relationships with their significant others were more frequently expressed by mothers in Mendoza. This might be explained

by the general attitude observed in Argentina about taking life as it is and not demanding solutions of problems as strong as participants in Spain.

Mothers in both regions had much more detailed and extended accounts referred to these needs than supporters and included the need of having a partner and social relationships outside family, the need of improving their relationships with their significant others, be understood and able to express themselves. Supporters probably were not aware of many needs that belonged to the more intimate sphere of the mothers' feelings and desires. This might point to a communication focused on practical aspects, which might be leaving intimate aspects aside. Needs of partner and more extended social relationships coincide with the description of socio-demographic characteristics and contexts, which showed a high percentage of women that were single and a tendency of women to have social contacts restricted to their close family. As well, not expressed by many but very significant, was the desire of living a normal life which included their children. This coincides with previous literature (Krumm & Becker, 2006; Montgomery et al., 2006) that showed how subjects with mental illness value normality and how they worry about their children and their future. These findings show an awareness of mothers regarding their situation of disadvantage and exclusion, a situation that has been more repeatedly mentioned among participants in Spain than Argentina. It is possible that societal awareness of these issues is higher, given the longer tradition of mental health care based on communitarian perspectives with a focus on societal integration. Supporting this explanation is the observation that only participants in Granada talked about the need of being accepted by society, when stigmatizing experiences had been accounted in both countries.

More mothers in Granada than in Mendoza talked about needing to improve their mood and keep stable in their mental illness. Improving their mood and self-esteem was mainly related by mothers to the feelings of anxiety and insecurity associated to parenting, and coincides with the higher frequency of mothers in Granada that expressed negative feelings about motherhood. It is also possible that mothers in Granada had a higher awareness of the manifestations of their illness and could articulate a specific demand for help.

5.4.2. Needs of support of mental health care professionals and other institutions

In general, needs related to professional care were overlapped with the more general needs in parenting that were mentioned before, e.g. having economic aid, being more active, improve their mood and solve problematic situations with their close social networks. Even when participants tended to be satisfied with professional care, they still considered that these more general needs they had, could be addressed by the health care system. This could be a sign of participants considering formal and informal systems of care as interrelated, cooperating and interacting in the caring relationship.

Regarding formal needs of care, the theme that was mostly mentioned by mothers was the need of receiving psychological support. Despite several types of care received, psychological care seemed to be lacking, and participants asked for it as a way to change their perspectives and cope better with their problems. Even when many mothers described how professionals were interested and helped in their problems in parenting, they required more intense follow up and dedication in this respect, showing an area where care could be improved.

In general, demands of formal care were much higher among participants in Spain than in Argentina. This does not seem to be related to a higher rate of uncovered needs in Spain, but to a higher awareness and demanding attitudes towards formal systems of care in that country. In Argentina, participants did not seem to expect much from mental health services, even when they described less support than in Spain. This is probably related to the type of care in Argentina which has traditionally been hospital based, a type of care that is more distant from the care receivers and their needs in daily lives. Despite the model of care being in transition, as was seen in the accounts of some participants which described experiences of care with a communitarian orientation, it seems that users still do not assume a more holistic approach to care as a right and do not demand more measures to be taken in this respect.

5.4.3. Needs of supporters

Even when the focus of the study was the support in parenting for mothers with SMI, caregivers in both countries stressed areas of own needs associated to their caring roles. The most frequent needs expressed by them were needs of respite, information about mental illness, emotional support and instrumental support. In general, we can observe these needs point out to a more general need of overcome the overload and burden they

were experiencing associated to their role and tasks of care. Noticeably, in Mendoza supporters expressed more needs of emotional support than in Granada, while they had expressed less emotional burden and higher satisfaction with received support when they talked about their experiences. It is possible that caregivers in Granada were actually experiencing more burden than participants in Argentina and therefore looked for and found more support, having less unfulfilled needs in this respect. It is also possible that these findings be explained by a cultural difference in the way of expressing negative aspects. In Argentina, participants might have been more reluctant to express negative experiences, but felt more comfortable to express these in terms of demand or need. The need of preventing emotional burden of caregivers and providing more information and orientation about mental illness and their role as carers, seem to be important areas to consider for future policy and program planning.

CONCLUSIONS

CONCLUSIONS

This study has given valuable insight into the experiences of support of in parenting of mothers with SMI and their caregivers, topics which have been little explored until now. It broadened existing knowledge to support the development of alternatives of care integrated in community settings, with emphasis on prevention and contextual evaluations of needs, in this case related to the parenting role of women with psychotic disorders.

The main features of the study consist in its qualitative and comparative design, and in the inclusion of caregivers as studied population. The qualitative design has allowed a deep understanding of mothers' and caregivers' experiences in relationship to parenting and informal care, as well as their needs of support in these areas. The understanding of the experiences of mothers regarding their care, can orient social networks to be more supportive and sensitive to mothers' needs. It can also orient professional care and institutional programs to be more adequate to their experiences, while addressing areas of greater need. Qualitative approaches, by allowing participants to deepen in their experiences and reflect on them, promote their recognition as autonomous individuals who can be active participants of their own care. The inclusion of caregivers as studied population has broadened the understanding of the dynamics of support and highlighted their role and own needs as figures of care. As well, caregivers were a complimentary source of information and a corroboration of the accounts obtained from mothers, adding trustworthiness to the study. Finally, the comparative design allowed a contextualized understanding of the accounted experiences. Similarities and differences in the accounts of participants were interpreted in relationship to their context, especially in relation to the different organization of mental health care in the two regions of study. Differences were observed not only regarding the ways in which difficulties were recognized and expressed, but also in the ways in which they were faced.

Limitations of the study are, on one side, brought up by the qualitative methodology, which gains in deepness but cannot provide statistically generalizable information. Still, it can provide analytic generalizations and transferability to similar contexts (Miles & Huberman, 1994; Polit & Beck, 2010). The transversal design of the study limits the possibility to consider the evolution of the experiences of parenting and care, and even when the

narratives had a temporal dimension, it is possible that most stories were influenced by the mood and experiences of the moment of interview. Finally, it is important to notice that the study lacks information about the situation of families that refused to participate in the study. It is possible that families facing more severe problems were more reluctant to talk about their experiences and rejected participation in the study. Hence, information could have been missed about more severe and problematic situations. Since recruitment was fully done through the mediation of professionals coming from mental health care services, it is also possible that people that had more tense relationships with professional care did not feel comfortable to participate in the study. Because of these reasons, it is necessary to be cautious about assuming similar experiences in all families in which a mother has a psychotic disorder. As was said before, information can only be extrapolated to similar settings and contexts.

In coincidence with previous studies, this research has shown a situation of vulnerability of mothers with schizophrenia in multiple areas of their lives, including difficulties in social and family integration, working integration and economic wellbeing. In Granada, mothers were slightly better integrated in social and working life. Nevertheless, in both regions women were economically vulnerable, due to economic difficulties or to lack of economic independency. This research also showed that some caregivers, especially in Mendoza, shared the condition of social and economic vulnerability of mothers. Caregiving tended to be assumed by family members, followed by partners, and organized around one main caregiver, accompanied by secondary figures of support that provided care with less involvement, intensity or duration. More men and partners acted as supporters when compared to caregivers of severely mentally ill people without children.

Caring for children was highly valued by mothers and supporters, and most families counted with a caring and affectionate environment in their homes. Mothers expressed positive aspects of maternity, and most could identify some strengths and confidence about their parenting capacities. Nevertheless, difficulties were identified in several areas of childcare and education, including problems related to discipline of children, negative feelings associated to parenthood, and difficulties in the interaction with children. Most participants from all groups considered difficulties to be caused by mental illness. Not only symptoms, but also the adverse effects of medications and stigma associated to mental illness could hinder parenting. Nevertheless, and without denying the difficulties of mothers, participants from all groups tended to consider the situation from the resource-

oriented perspective, mentioning the ways in which mothers and supporters faced problems and organized aid so to overcome them. Both, mothers and caregivers in both sites of study, were aware of the influences of a supportive context in parenting.

Support coming from the close social network was considered as fundamental to overcome difficulties in parenting. Support was provided in several areas of mothers' lives that directly or indirectly affected parenting, showing a comprehensive understanding of parenting and the complexity of factors that can influence it. Main activities of supporters were related to the most problematic areas in childcare, namely interaction between mother and child, discipline, and provision of adequate material conditions for childcare.

All activities of support tended to be immersed in a caring relationship in which the mother kept an active role, but not always reaching independency or symmetrical relationships with their caregivers. Main problems regarding support included difficulties in the interaction between mothers and supporters, and among different figures of support. Other frequent problems included disagreements, feelings of displacement of mothers in their role, support hindering mothers from a full evolution and involvement in parenting, worries about the future and caregivers getting burdened by their activities. Problems could be so intense that they could invalidate or diminish the effectiveness of support, especially in the eyes of mothers. Burden was a common experience for most caregivers. The main source of burden was emotional overload associated to their role, but also to their concerns about children. In Argentina, social burden was also common, associated to limitations in social life caused by their caring responsibilities. Positive aspects were likewise identified by most caregivers.

During moments of psychotic relapse, care had to be reorganized and became more intense. In both places caregivers were responsible for noticing signs or relapse and finding appropriate care. In Argentina mothers with psychotic relapses were more frequently hospitalized than in Spain, where crisis tended to be managed at home and hospitalizations tended to be brief. During psychotic breakdowns caregivers had to fully take care of children, and when crises were managed at home, to care for the mother. This lead to an overload of tasks which required additional help of family or neighbors. In both places, secondary figures of support became more involved during moments of relapse, showing adaptability and capacity of response of the network of support during moments of greater need of care.

Regarding needs of support, all groups talked about several areas of life in which mothers needed support and would directly or indirectly affect parenting. As was observed with activities of supporters that indirectly addressed parenting, this shows a comprehensive understanding of parenting as a process that can be affected by several aspects of mother's lives and contexts. Needs of support in parenting were mainly related to the need of counting with more direct interventions with children, economic support and orientation and advice regarding childcare. In areas indirectly related to parenting, needs were mainly identified regarding the need of more activity and independency, and needs of improving emotional aspects of support. Caregivers talked about their own needs related to their roles as carers, including needs of respite, emotional support and more instrumental support from other family members or people from their close environments. These needs point to a more general need of reducing their overload and burden. Regarding professional and institutional care, the most frequent need participants mentioned was more psychological support so to cope better with their problems. Some supporters also required psychological support for children, and in Mendoza, occupational therapy for mothers. As and aid for themselves, caregivers especially demanded more information about mental illness, delivered timely.

Summarizing the differences between the accounts of different groups of participants, mothers recognized less difficulties in childcare, less difficulties in children and less activities of care than caregivers. They also considered themselves to be more involved and responsible for children than what caregivers considered them to be. These differences can be explained by a lower awareness and insight of participants on some of their difficulties, but also as caused by shame, fear, and the need of presenting a more positive image of themselves. Supporters identified more difficulties of mothers regarding childcare and more difficulties in children than mothers. As well, they tended to think of themselves as more involved and responsible for childcare, and to consider support from context as fundamental for an adequate parenting and wellbeing of children. On the other side, caregivers tended to ignore some aspects of the maternal experiences that mothers considered fundamental. These were especially related to mothers' satisfaction with received support, stigmatizing attitudes mothers were perceiving from their networks of care, and some needs of mothers related to their intimate and emotional lives. As mothers, caregivers might not be aware of own prejudicial behaviors in the interaction with mothers, and might present a positive image of themselves omitting shameful or guilt causing aspects of their experiences. Besides, differences in their accounts show areas in which

communication between mothers and caregivers could be improved, so to readjust their expectations and prevent frustrations within their interactions.

Despite the different organization of mental health care services in both countries, hospital centered in Mendoza and community centered in Granada, practices associated to community mental health care approaches were being used in both regions. These practices included care provided by interdisciplinary teams, care that addressed social needs of patients, and the inclusion of families in care. Nevertheless, these practices had different degrees of organization and implementation in both countries, probably reflecting a more developed community health care model in Spain and a psychiatric care model in transition in Argentina. Participants in Granada tended to count with more institutional support from mental health care services and professionals in parenting roles and in other aspects related to the social dimensions of illness. The role as parents of their patients was acknowledged with more frequency by professionals of mental health care services in Granada, and difficulties in parenting were also addressed with higher frequency. Mental health care services in Granada were more accessible for users given their integration to the network of primary health care, counted with more programs for the social integration of the mentally ill, and with a follow up program for families in which a parent has a severe mental illness. As well, caregivers received more acknowledgment and support in their role from mental health care services than their counterparts in Mendoza. In Mendoza, some mothers received support in parenting coming from mental health care professionals and services, but in general these services tended to be more focused on psychopathological aspects than on social dimensions of illness. In Mendoza, shortfalls of mental health services were frequently compensated by other institutions, like schools, police, courts and religious institutions. With all, mothers and caregivers in Mendoza counted with extended family support regardless of the organization of formal care, and mothers seemed to make more use of community resources not related to mental health care services than mothers in Granada. This can reflect a capacity of mothers and their families to overcome difficulties and address their needs independently from health care services.

Community mental health care principles seemed to have an impact beyond institutional practices, influencing daily life experiences of mothers and caregivers and the ways of understanding their roles and activities. Mothers in Granada tended to be more confident and assured in their mothering role, and tended to be more independent and active in general than mothers in Mendoza. Besides, they and their caregivers tended to talk with

higher frequency than in Mendoza about the importance of being reaffirmed in their roles, and of carrying on independent and autonomous lives. These findings reflect some of the most important goals of community mental health care, related to the promotion of autonomy, social integration and participation of individuals with severe mental illnesses in their own care. Coinciding with the importance given to family as resources of care in community mental health care paradigms, caregivers in Granada seemed to be more educated about mental illness in general and about their role as caregivers. The higher education in these aspects had an impact in the accounts of supporters, since they managed some concepts which allowed them to name and articulate with more clarity some of their activities and functions. But a higher education in these aspects also seemed to have an influence in the way care was provided, as shown by a less frequent use of restrictive strategies of care than in Mendoza, and the lower perception of mothers being displaced by caregivers in their roles when compared to Mendoza.

The promotion of autonomy, social integration, inclusion of families and care receivers in their own care were also present among participants in Mendoza, and were explicitly mentioned by mothers and caregivers. Yet, more restrictive models of care tended to be more frequent in Mendoza, with more mothers being less active, displaced in their roles by caregivers, and keeping a passive role in the organization of care and interaction with their supporters. This probably reflects the transition to a community mental health care model in Argentina, during which more traditional and restrictive practices remain present and coexist with more integral community approaches.

Other differences between countries could be observed in several areas of the accounts of mothers and caregivers. In Mendoza, there was a tendency to complain less about difficulties, and to accept present circumstances with higher resignation and less expectations of change. As well, participants in Mendoza tended to normalize many of their difficulties and the interaction between mothers and caregivers and the difficulties that appeared in it.

Recommendations and implications for future mental health care programs and research

These findings have interesting implications for future mental health policies and programs. First, health care professionals and institutions need to acknowledge the role as parents of people with SMI and adjust the organization of care to their time limitations, adjust treatments to their needs of keeping active and awake, organize more specific

measures of support in parenting, and optimize the interaction between formal and informal care so that caregivers are better educated and supported in their role.

It seems especially important to consider that support be organized in a way that mothers do not result displaced in their role, do not result disempowered, and do not loose own capabilities because of receiving aid. As most mothers showed difficulties in some areas or parenting, while showing strong competences in others, support in parenting should be specific for the areas in which problems are present. In this way, the capacity of agency and autonomy of mothers would be respected in the areas in which they do not present problems. With the same goal, to provide support in areas in which they present difficulties, the first strategy to implement would be to stimulate and develop the mother's own parental competences. Mediation of their interaction with children, provision of guidance and advice and aid to organize daily activities with children seemed to be adequate strategies to improve parental competences in several cases. Only if these strategies result to be ineffective, or in cases of unavailable mothers or immediate needs of care of children, caregivers can take on parenting tasks instead of mothers. This was also required by mothers when they felt too overloaded or needed time to dedicate to other tasks.

As well, it seemed fundamental that mothers be active participants in their care through direct participation in caring activities or through the reciprocation of support in other areas. Interactions between mothers and caregivers should be improved, as well as their communication about the more frustrating aspects of receiving and providing care. For most mothers the way in which support was provided was as important as the activity performed by the caregiver and the need it was intended to cover. Support should not only be accessible but also acceptable, so to be effective.

Especial attention should be given to the need of improving social integration of mothers, improving existent social relationships, and work on stigma associated to mental illness and maternity, since it hinders mothers in their social interactions and search of aid within their communities but also with institutions.

It also seems of fundamental importance that caregivers be included in mental health care services and programs, so to provide more information about mental illness and clarify aspects of their role as supporters, mediate the interaction with the mother and children, and avoid burden. Efforts to expand the network of support are needed, and seem of special importance in families with children in which caregivers face additional overload of

caring responsibilities. As well, families need to be prepared in advance for periods of higher demand of care, especially during psychotic breakdowns. Mental health care services can help to organize the network of care, but also provide more support during these moments giving adequate information, emotional support and additional instrumental aid when needed.

Future research could address a higher number of participants and include a design capable of finding correlations among different aspects of the context, illness and dynamics of care, and their impact on mother, child and families' wellbeing. In this way, findings of this study could be prioritized and subjective views could be strengthened by a more objective approach. A longitudinal design could be useful so to understand continuity of care, and how experiences change over time and in different moments of the evolution of illness and development of the child. Finally, it would be interesting to include the experiences of fathers with psychotic disorders, since the present study only focused on motherhood and severe mental illness.

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